DOCUMENT RESUME

ED 464 243 CE 083 203

AUTHOR	Alaszewski, Andy; Motherby, Elaine; Gates, Bob; Ayer, Sam; Manthorpe, Jill
TITLE	Diversity and Change: The Changing Roles and Education of Learning Disability Nurses. Researching Professional Education Research Reports Series.
INSTITUTION	English National Board for Nursing, Midwifery and Health Visiting, London.
REPORT NO	ENB-RR-21
ISBN	ISBN-1-901697-71-1
PUB DATE	2001-00-00
NOTE	166p.; For research highlights, see CE 083 204.
AVAILABLE FROM	English National Board for Nursing, Midwifery and Health Visiting, Publications Department, Victory House, 170 Tottenham Court Road, London W1P OHA, England, United Kingdom. Tel: 0207-391-6314; e-mail: pubs@enb.org.uk.
PUB TYPE	Reports - Research (143)
EDRS PRICE	EDRS Price MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Caregiver Role; Developed Nations; Education Work Relationship; Educational Needs; Educational Research; Foreign Countries; Higher Education; Interprofessional Relationship; *Job Skills; *Learning Disabilities; Medical Services; *Nurses; *Nursing; *Nursing Education; *Nursing Research; Occupational Information; Outcomes of Education; Postsecondary Education; Role
IDENTIFIERS	Nurse Patient Relationship; United Kingdom

ABSTRACT

This report examines the current roles of learning disability (LD) nurses within multi-professional and multi-agency teams in a range of care settings. It also studies the effectiveness of current educational provision for LD nursing and the contribution of users and carers. Chapter 1 describes the following research methods: questionnaires; case studies; nurse diaries; and focus groups. Chapter 2 traces development of services for people with LDs and the associated development of LD nursing. Chapter 3 examines the current roles of LD nurses and finds that the role of junior nurses is as provider of direct user care, with more experienced nurses moved into more specialist or managerial roles. Chapter 4 explores relationships between user and LD nurses and finds that the role of the LD nurse is as a source of expertise and support. Chapter 5 looks at ways educational institutions approach nursing education and reports they aim to produce flexible nurses who have the ability to adjust to changing situations through lifelong learning. Perceptions of the learning process, especially the development of appropriate skills and findings nurses believe nurses' knowledge has improved, their skills are reduced, and they are not as well-prepared for practice are examined in chapter 6. Chapter 7 is a summary and highlights items that need to be addressed in the nursing curriculum. (Contains 182 references and 30 tables.) (YLB)

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Diversity and Change: the changing roles and education of learning disability nurses

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RESEARCHING PROFESSIONAL EDUCATION

A series from the English National Board for Nursing, Midwifery and Health Visiting

Diversity and Change: the changing roles and education of learning disability nurses

Andy Alaszewski
Elaine Motherby
Bob Gates
Sam Ayer
Jill Manthorpe

London, 2001

Published by
The English National Board for Nursing, Midwifery and Health Visiting,
Victory House, 170 Tottenham Court Road, London W1T 7HA
Telephone: 020 7388 3131
Fax: 020 7383 4031
E-mail: pubs@enb.org.uk
www site: http://www.enb.org.uk

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ISBN 1 901697 71 1

This report has been prepared for publication by
Jill Rogers Associates, Cambridgeshire
Design by Sadler, Suffolk
Printed by Piggott Printers Limited, Cambridge

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Acknowledgements

We would like to thank the English National Board for Nursing, Midwifery and Health Visiting for providing the funding for the research on which this report is based from July 1998 until July 2000.

The research team would also like to thank the members of the Steering Group for their support, constructive comments and guidance throughout the two years of the project. In particular we thank Gordon Grant, who chaired the meetings and Sonia Crow, who maintained a close interest in the research and provided us with advice and guidance. We found the comments of the anonymous reviewers who commented on the first draft of our final report helpful.

We would also like to thank the numerous educationalists, students, nurses and employers who participated in and contributed to the projects and all the members of the users and carer groups. We are unable to acknowledge the contribution of the participants in this research directly as we have used pseudonyms to ensure anonymity throughout this report.

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Abbreviations

CCETSW	Central Council for the Education and Training of Social Workers
CFP	Common foundation programme
CMHT	Community mental handicap team
DoH	Department of Health
GNC	General Nursing Council
PREP	Post-registration Education and Practice
QAA	Quality Assurance Agency for Higher Education
RCT	Randomised control trial
RNMH	Registered nurse, mental handicap
SSD	Social services department
UKCC	United Kingdom Central Council for Nursing, Midwifery and Health Visiting

Foreword

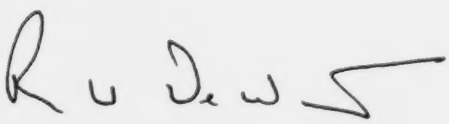
The English National Board for Nursing, Midwifery and Health Visiting is delighted to publish this report as the twenty first in its successful series: *Researching Professional Education.*

The Board launched this series with the aim of making widely available the results and implications of research commissioned by the Board. The series enables key stakeholders: policy makers, managers, practitioners, researchers and educators to have access to relevant and sound research from which to plan educational developments.

This latest report, *Diversity and Change: the changing roles and education of learning disability nurses*, examines the current roles of learning disability nurses within multiprofessional and multi-agency teams in a range of care settings. The research team also examined the effectiveness of current educational provision for learning disability nursing and the contribution of users and carers.

Major differences were identified in the roles of learning disability nurses from the provision of care and support within hospital settings to a diversity of roles and activities providing support for users in a variety of settings. The research shows that learning disability nurses make a major and distinctive contribution to the multiprofessional and multi-agency teams with whom they work. In terms of educational provision, the role of users and carers needs to be reviewed and they need to be treated as active partners not as passive bystanders.

This important report has implications for educational providers, for employers of learning disability nurses and the members of the teams within which learning disability nurses work.



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London, 2001

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1.1 Introduction

This chapter presents the methods used to collect evidence for our study of learning disability nursing. The research built on the case study approach developed in our study of nurses' educational preparation for assessing and managing risk in community practice (Alaszewski et al., 2000). An additional survey provided an overview of the current development of learning disability nursing.

1.2 Evaluating nurses' educational preparation

In social research, there is a variety of approaches to the collection and analysis of information. Since each has its own strengths and weaknesses, researchers' choices are guided by the appropriateness of particular methods for achieving their aims and objectives (Woods, 1997).

1.2.1 The quality of educational preparation

Our research was commissioned by the English National Board for Nursing, Midwifery and Health Visiting (the Board) to evaluate the educational preparation of learning disability nurses to provide care and support for individuals with learning disabilities within the context of multidisciplinary care. As Lishman has pointed out, this type of research needs to consider a range of factors: *'Evaluation examines our effectiveness and can help us to improve it, can increase our accountability to users and clients, develops our knowledge and identifies gaps in practice and service delivery'* (Lishman, 1999: 1). Thus, evaluative research is concerned with the quality of provision, and we start our consideration of methodologies with a discussion of competence.

Eraut noted the term 'competence' was initially used in Britain in relation to qualification. Offering one definition as *'the ability to perform the tasks and roles required to the expected standard'* (Eraut, 1998: 129), he added that such a definition has the advantage of ease of application and may be applied to all stages of people's careers. However, he argued that it was harder to apply to jobs with multiple roles and failed to consider whose requirements should be pre-eminent. He therefore proposed that the definition should be joined by a sense that while *'competency is an underlying characteristic'* it is also *'a combination of attributes'* (Eraut, 1998: 134).

This study is concerned with the quality of nurse education, especially its contribution to the development of learning disability nurses' competence. As Pfeffer and Coote (1991: i) noted, the concept of quality is *'slippery and the meaning elusive'*. This is especially true when an organisation's product is a service, such as education. As Cameron-Jones (1988: 65) pointed out, discussion about the nature of teaching quality *'often slides into areas that are merely hopeful, or just mystical or, most frequently, moral and/or personal and therefore very difficult to measure'* (Cameron-Jones, 1988: 65). Thus we begin with a discussion of alternative approaches to quality, identifying the approach which we considered most appropriate for our study.

1.2.1.1 Quality as consumer satisfaction

Given the difficulty of defining the quality of services, some discussions shift the emphasis from the product to perceptions of the product. Ellis (1988: 7) suggested that *'quality is that which gives complete consumer satisfaction'*. This 'consumerist' approach has been described in the following way: *'Quality according to this approach, is achieved through constantly striving to achieve customer requirements'* (Pfeffer and Coote, 1991: 10).

1.2.1.2 Quality as universal standards

The universal approach is based on the establishment of standards against which a product can be assessed. Ideally these should be objective and based on independent and publicly verifiable criteria. In this 'traditional' or 'common sense' view, only a few products are adjudged to be high quality, and therefore this approach is sometimes referred to as the 'Rolls-Royce' approach.

1.2.1.3 Quality as professional standards

It is difficult to precisely specify the product of welfare services (and indeed the customer for that product) and it is therefore not easy to agree criteria for assessing their quality. Because of this a weaker definition or specification of quality is often used; professionals have traditionally *'relied on the specification and monitoring of input standards'* (Evetts, 1999: 125).

This approach has become dominant within the NHS commissioning process. Agreed quality standards are included in contracts between purchasing authorities and service providers, and are meant to safeguard patients. They should be clearly identifiable and quantifiable, but are generally derived from professional, i.e. medical and nursing, standards. Quality is not defined in terms of ideal standards, but as a set of minimum standards. However, clinical governance looks set to put in place more inclusive and systematic methods for assuring and improving health care quality (Dewar, 2000), and such developments are likely to cascade into the educational setting.

1.2.1.4 Quality as fitness for purpose

An alternative approach is to judge quality in terms of the task the product is designed to perform. The emphasis is on the 'right quality' for the purpose, and factors such as cost will be included in this assessment. The British Standards Institute defines quality as *'the totality of features and characteristics of a product or service that bear on its ability to satisfy a given need'* (BQA, 1987).

One of the difficulties in this approach lies in defining the purpose of the product. In the private sector, it may be possible to compare the characteristics of different products. However in the public sector, public agencies are often sole producers and the purposes of production are defined through political rather than market processes. Thus it may be more appropriate to consider the objectives which a particular agency is designed to achieve.

1.3 Evaluating the quality of nurse education

Since nurse education is publicly funded, the various funders have an obligation to assure the quality of the education they commission. In October 1997 the Quality Assurance Agency for Higher Education (QAA) took responsibility for assessing the quality of higher education and it seeks to operate collaboratively with professional and statutory bodies such as the Board. Its main approach is to assess the fitness for purpose of teaching. The purpose of educational provision is defined by the providers of the education in a self-assessment document.

There has been a convergence in both the procedures and criteria used to evaluate professional and non-professional education. The recent round of reviews by the QAA were undertaken jointly with the English National Board. Attempts to identify a baseline for the evaluation of professional education indicate that it serves a multiplicity of 'purposes'. For example a study commissioned by the NHS Executive and the Higher Education Quality Council (1996), identified three main purposes:

- fitness for purpose – the major concern of commissioners – is ultimately measured in terms of the employee's competence and capabilities

- fitness for award – the major concern of education providers – relates to academic judgements about level, scope and attainment in learning, and is applicable both to learning programmes and those undertaking them
- fitness for practice – the major concern of professional statutory bodies – determines whether an individual can be licensed/registered (or re-registered) as a professional practitioner.

We accepted as the basis of our evaluation a definition of quality as 'fitness for purpose'. Given the major changes in approaches to care and role of learning disability nursing (described in Chapter 2), there were no generally accepted objective or professional standards. However, the consumer perspective formed an important element of our research, and we explored user and carer perspectives on nurses' roles and therefore the purpose of current nurse education.

Our research had two interrelated elements: the first was designed to describe the development, nature and range of contemporary learning disability nursing practice emphasising:

- the roles of learning disability nurses in relation to service users and informal carers within the context of multiprofessional and multi-agency work
- the skills and competencies which learning disability nurses need to perform these roles.

The second element was designed to evaluate the extent to which current educational provision prepared learning disability nurses for this range of roles and associated competencies by examining:

- the aims and structure of current provision
- the ways in which current provision prepared learning disability nurses for supporting individuals in the community
- the ways in which current provision prepared learning disability nurses to contribute to 'seamless' multidisciplinary and multi-agency care.

1.4 Choice of research design

1.4.1 Experimental designs

A variety of research designs can be used to carry out evaluative research. Traditionally within medical research particular prominence has been given to experimental designs, especially randomised control trials (RCTs). Cochrane (1972) advocated them as experiments that would evaluate the effectiveness of clinical medicine and practice.

A successful RCT requires laboratory-like control of conditions and measurement of outcomes so that the hypothesis can really be tested. Although this approach could in theory be used to evaluate nurse education, in practice it would be difficult to gain sufficient controls or clear enough measures. It was unsuitable for our study, as our range of objectives was too wide, and even if we could have defined the key variables, we certainly could not have controlled them.

1.4.2 Case study design

In the 1940s and 1950s, researchers started to use ethnographic case studies to explore 'deviant communities' such as a slum community (Whyte, 1955) or mental hospitals (Goffman, 1968) and from there the approach has become more generally accepted. Yin (1994) saw it as a distinctive research strategy that aims to capture the unique features of a case and to interpret them within their real-life context.

The starting point for any case study is the definition of the cases to form the basis of the study. In this research the case can be defined as the current educational preparation of learning disability nurses. While we seek to capture objective features of this process, such as

the content of current programmes, we are also interested in subjective interpretations, especially those of students; indeed an important reason for using a case study design is to explore the interaction between the objective and subjective nature of the process.

Case study design permits the triangulation of data, and we sought to complement quantitative data derived from social survey research with qualitative data derived from naturalistic research.

1.4.3 Social survey

We used survey methodologies to collect quantitative data. In social surveys information is collected from specific units, using a standard set of procedures such as a questionnaire or a structured form.

Surveys, especially those using questionnaires, are seen as a cost-effective way of generating large quantities of good quality data (Denscombe, 1998). Murphy (2000) identified a number of advantages of questionnaires, including:

- distribution in large numbers
- cheaper than other methods of data collection
- ease of administration
- designed properly, analysis can be easy
- anonymity
- no training required
- reduced interviewer bias.

The survey offers considerable advantages; not only is it flexible but it also enables a substantial amount of data to be collected in a form that facilitates both comparison and analysis. Thus we used survey methodology in both elements of our research. We undertook a national survey of 10% of all nurses on the learning disability parts of the Professional Register currently held by the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC). We also surveyed all current Board-approved programmes in this area of practice exploring their aims and objectives and the ways in which they sought to achieve them.

1.4.4 Naturalistic research

While social surveys provide a cost-effective way of collecting large quantities of data, the explanatory value of these data is often limited. This type of research may be able to describe *what* people do but it will not fully explain *why* they do it. Accessing individuals' interpretations of their world is the only way to do this.

The only way that researchers can obtain such data is to become part of the 'natural setting' (Fielding, 1993) by participating in the social life of the people being researched. Naturalistic researchers are committed to seeing the world from the social actors' point of view; to do this they seek to participate in the everyday life of a community so that they can see the world from the point of view of a member of the community.

We used a naturalistic approach to achieve some of our research objectives. Learning disability nurses have had to adjust to a rapidly changing environment and while a number of prescriptive studies indicate what they should be doing there is far less evidence of what they do and why. We supplemented quantitative data with qualitative data to explore stakeholders' perceptions of both the nursing role and of the extent to which current education prepared nurses for this role. Thus we accessed the views not only of students and lecturers but also practitioners, employers, users and carers through focus groups, and accessed the role of current nurses through observation and diaries.

1.5 Researching the role of learning disability nurses

The first phase of the project set out to establish the roles and activities of learning disability nurses. The aim was to build up a picture of what they do as members of multiprofessional, multi-agency teams so that, after examining what they are taught, we could assess their preparation for practice. The overall aim can be split into two specific aims:

- analyse the discrete role of the learning disability nurse within the multiprofessional and multi-agency team in a range of care settings
- assess the effectiveness of educational outcomes in professional practice in relation to the perceived needs of service users and carers and the roles and activities of nurses within multiprofessional, multi-agency teams.

1.5.1 The questionnaire

A questionnaire was used to gather information to examine the development and nature of nurses' current practice and educational experiences. The information enabled us to build up a profile of learning disability nurses as well as accessing their views on their past experiences of, and thoughts on, current nurse education.

The questionnaire contained 50 questions on respondents' personal information, initial nurse education, career development, personal and professional development, current employment and thoughts on nurse education. The majority of questions were open-ended to encourage detailed responses.

The questionnaire was piloted with a sample of learning disability nurses in Wales, after which some minor alterations were made; these mainly involved modifications of phrasing. The majority of respondents in the pilot study wrote that they enjoyed completing the questionnaire, found the questions clear and straightforward, and thought the presentation of the questionnaire was satisfactory.

The population for our main study was all 18,640 nurses on the learning disability Parts of the Professional Register in March 1999. It was neither cost effective nor practicable to include the whole population within the study, therefore we decided to select a representative sample that would enable us to generalise our findings to the whole population. As Najman et al. (1992) noted, the major requirement for a representative sample is that it is chosen in a random manner.

The UKCC advised us that when nurses provided the appropriate evidence their names were added randomly to the appropriate register. Therefore the sampling process was simple and straightforward, as they had the capacity to select and print names and addresses at specified intervals. To protect confidentiality, the printed lists were held by the UKCC, and all labelling and posting of initial and follow-up questionnaires took place from the UKCC. We did not know anything about the nurses who received our questionnaire – other than that they were first or second level learning disability nurses – until the completed questionnaires were returned.

The size of a sample also influences the extent to which the findings can be generalised to the whole population. In particular it influences the statistical assessment of probability that observed differences were due to chance. We decided to take a 10% sample. Given that large-scale unsolicited postal questionnaires tend to have relatively low response rate, usually below 50%, this would mean would should get around 550 respondents, which would be adequate for most tests of association (Najman et al., 1992).

Our questionnaire was distributed to the 1,864 nurses in the sample in March 1999, accompanied by a leaflet on the project, a letter explaining the purpose of the questionnaire and a freepost envelope for its return; the initial response rate was 404 (22%). The first follow up took the form of a postcard inviting nurses to return their questionnaire or contact us if they

required another copy. This generated approximately 66 requests for further questionnaires and 104 additional questionnaires were returned, giving a total of 508 (28.1%). The final reminder was sent out in June 1999; nurses who were yet to respond were sent a covering letter explaining the purpose of the research, another questionnaire, and another freepost envelope. An additional 248 questionnaires were returned making a final total of 756 (41.9%). While the response rate is disappointing, it is comparable to those of other large-scale surveys of nurses (e.g., UKCC, 1999a; 1999b).

One way of assessing the bias that may be created by a differential response rate is to compare characteristics of the sample with known characteristics of the whole population. We are not aware of any studies of the whole population, but there have been two studies of cohorts of qualified learning disability nurses (Brown and Walton, 1984; Robinson et al., 2000 – undertaken in 1997-98); both include data for the gender composition of the cohort and the later study includes data for ethnic composition. The 1984 cohort reported 31% male, while the later study reported 22% male; our study was in between with 29% male. In terms of ethnic composition, 93% of the 1997-98 cohort reported themselves as white and 6% as Asian or black; in our study 88% reported themselves as white and 12% as Asian or black; however 4% reported themselves as Mauritian, an ethnic group which was actively recruited to work in this area of nursing in the 1960s. These data indicate that our sample is similar in terms of gender and ethnicity to the other two cohorts.

The data generated by the questionnaire were analysed using SPSS, a statistical analysis computer package. Additional quotes and comments were copied into a separate file, then this was subjected to content analysis. These data were then coded and entered into the SPSS database and treated in the same way as the answers to closed questions, so that there was equivalence of analysis. Two researchers independently categorised the findings then compared and agreed their categories. This approach was used to analyse all qualitative data generated in the project.

1.5.2 Researching practice

The case studies were designed to explore in more detail the current role and practice of learning disability nurses, their roles in multidisciplinary teams and the effectiveness of educational preparation. The multidisciplinary teams were selected to represent different types of team and areas of practice, and therefore reflected different types of settings: statutory services such as the NHS and local authority social services, and the voluntary and private sector; and different forms of service provision: forensic, residential, day care or family support. Ten teams were included in the study (Table 1.1).

Team	Setting	Sector	Nurses	Others in the MDT
1	Residential home	Private	1 RNMH 1 EN (MS)	3 Health care assistants (including deputy home manager)
2	Community team	NHS	4 RNMH	Care manager (social worker) Therapies manager (OT) Occupational therapist Social worker
3	Day care centre	NHS	1 RN (LD) 2 RNMH	Senior physiotherapist 2 Health care assistants
4	Forensic unit	NHS	1 RNMH 3 RN (LD)	General practitioner Social worker 2 Health care assistants
5	Nursing home	Charitable organisation	3 RNMH 1 EN (MS)	3 Health care assistants
6	Specialist nurses	NHS	2 RNMH	
7 & 8	Hospital wards (learning disabilities)	NHS	2 RNMH 1 RN (LD)	Doctor
9	Day care and respite unit	NHS	1 RN (LD)	Physiotherapist
10	Placement unit (involved in placing adults with learning disabilities with carers in the community)	Independent/ local authority	1 RNMH	

Key: RNMH *Registered Nurse for the Mentally Handicapped*
EN (MS) *Enrolled Nurse (Mental Subnormality)*
RN (LD) *Registered Nurse (Learning Disability)*

Table 1.1: Teams included in the case studies

More than half of the case studies were undertaken within NHS settings. This reflects the findings of the questionnaire, which showed that the majority of respondents were employed within the NHS.

The teams included in the case studies were recruited using a number of methods. Several approached the researchers after reading about the project and asked to be involved. Others were approached through contacts, whilst one was invited to take part after a team member indicated interest in the questionnaire. Care was taken to ensure that they represented different settings, geographical areas, and types of practice. We had difficulty in identifying nurses working within local authority settings – three local authorities were approached and were unable to identify any learning disability nurses currently employed by them. We therefore included Team 10, a learning disability nurse working for an organisation which 'placed' adults with learning disabilities with paid carers in the community. She was employed by an independent organisation, but the local authority funded the project.

The research team aimed to capture the unique features of each case so that the practice of learning disability nurses could be seen within its real-life context. A variety of data were collected. The researchers interviewed the learning disability nurses at the beginning and at end of the day spent under observation. The initial interview was used as a short introduction and considered:

- personal information about the nurse
- career development information
- the role of the learning disability nurse
- evidence of shared learning

- role in relation to teamwork
- general information about the day ahead.

The researcher then spent the day observing the nurse in practice, made notes on the activities the nurse undertook – including interactions with other team members, and sought clarification from the nurse as necessary. The observation allowed a brief insight to the roles of the 24 nurses who took part. Towards the end of the day an interview took place with the aim of debriefing the nurse and examining the following areas:

- how the nurse felt the day went
- whether the nurse could identify any areas requiring further input in terms of training or education
- views on the future of the profession
- personal career development plans
- any issues that arose during the day.

All interviews were tape-recorded and notes were made by the researcher. The recordings were transcribed and the data from the transcripts were coded and analysed to identify any recurring themes. Responses to the core questions were themed in order to make this analysis easier.

The roles and activities undertaken by the nurses during observation were broken down into the areas of knowledge, skills and attitudes. This enabled the research team to build up a picture of the knowledge, skills and attitudes required by learning disability nurses in contemporary practice. These findings supplemented the data generated by the questionnaire.

1.5.3 Nurse diaries

One day of observation does not usually give a clear picture of the overall role of individual nurses, so the nurses were invited to complete diaries for a 10-day period following the observation. They were given clear verbal and written instructions about what to include, and notebooks to use as diaries.

Out of the 24 nurses who were observed, 16 returned completed diaries. Those who failed to do so indicated that they did not have the time to complete the diary.

The diaries were analysed, and findings were broken down into different areas. We were able to further identify the knowledge, skills and attitudes used in current practice, and areas where these nurses considered that they would perhaps benefit from further training or education.

Where possible, members of the multidisciplinary team were also interviewed to explore their perceptions of the role of the team, their own role and that of the nurse member(s). Some nurses worked in areas which made it difficult to approach other team members, either because of the location of their practice or because their colleagues were unavailable at the time of our visit; everyone we approached agreed to take part. The interviews took place on a one-to-one basis, and interviewees were assured of confidentiality. The aims of the project were explained and they were given the opportunity to ask any questions. The interview looked at the following themes:

- team member's career development
- role within the team
- how they perceived the role of the nurse members
- thoughts on the educational preparation of learning disability nurses.

At the end of the interview the team members were given the opportunity to make additional comments. The interviews were recorded and transcribed; the research team then analysed the transcripts to identify any emerging themes. In total, 19 members of the multidisciplinary teams, other than learning disability nurses, were interviewed.

1.5.4 Focus groups with service users and carers

In the case studies the research team had the opportunity to observe how the nurses interacted with users and carers. However, it was not possible in that context to examine users' and carers' perspectives of the role of professionals and the adequacy of educational preparation. We decided to use focus group methods to investigate this, since these are an efficient way of collecting experiences and opinions in a non-threatening manner (Barbour and Kitzinger, 1999).

This research drew on prior experience of research (Alaszewski et al., 1998; Alaszewski et al., 1999; Manthorpe and Stanley, 1999) among vulnerable adults and drew on the burgeoning literature related to focus groups. Stalker et al. (1999) conducted interviews with 25 focus groups and six individual face-to-face supported interviews with people who had specific communication difficulties. In common with this research they accepted:

- service users are not a homogeneous group
- carers' and service users' views may differ
- pre-existing familiarity may enhance responsiveness to research.

There are some differences between Stalker et al.'s project and this research. Stalker et al. included a convenience sampling technique to identify a wide range of both users and carers and were able to elucidate comment on a wide range of services. The participants in our focus groups were drawn from a limited pool of respondents, but as Morgan (1988) argued, such bias is a problem only if you ignore it and interpret what you hear as representing a full spectrum of experiences and opinions.

Some commonalities of approach existed between Stalker et al.'s research and this project. Topic guides were produced to help the facilitators and both projects attended to matters of accessibility, confidentiality and sensitivity. Both tape-recorded the interviews with permissions, and used similar techniques in analysing the data and identifying emerging patterns and themes.

Crabtree et al. (1993) noted that the interview dynamic of a focus group turns the group itself into the unit of analysis and that the group process generates data and insights into the research topic. As Stewart and Shamdasani (1990) observed, this may result in aspects of synergy, snowballing, stimulation, security and spontaneity. We were able to see evidence of such dynamic effects, both among people with learning disabilities and the carers. Further dynamic interaction was also observed between the focus group respondents and the facilitator.

In part this may be explained by respondents' prior acquaintance with each other. As Khan et al. (1991) argued it is difficult in some areas to find individuals who are unknown to each other. Within many localities, for example, close networks exist between parents of children with disabilities. Many disabled people will also have encountered each other previously, either through segregated services or informal contacts. Murphy et al. (1992) concluded that existing networks might be particularly relevant to health-related research.

Eight focus groups were held in the latter half of 1999. Three were composed of people with learning disabilities, one was made up of seven family members and two people with learning disabilities and the final four were composed of family members, mostly parents. The groups came from a range of urban and rural locations throughout England and were a mix of voluntary support groups or established user groups meeting within day service settings.

Prior to the interview the purpose of the research and uses to which material would be put were discussed, and careful explanations and assurances of confidentiality were given.

The same researcher facilitated the groups and the interviews were recorded and transcribed. Analysis of the transcripts was initially undertaken by one researcher who employed a grounded theory approach, which comprised detailed reading of the transcripts to locate emerging themes and sub-themes, which were refined and shaped into material relating to the broader aspects of the research.

The focus groups addressed the following themes:

- level of contact/awareness of learning disability nurses
- the role of the learning disability nurse
- the learning disability nurse's distinct roles
- contact with learning disability nursing students
- involvement of participants in the educational preparation of learning disability nurses.

1.6 Educational preparation for practice

The second part of the study was designed to evaluate the educational preparation of learning disability nurses for their contribution to the multiprofessional, multi-agency team. The specific aims of this part of the project were to:

- evaluate the development and application of relevant research-based theory and evidence-based practice of pre- and post-registration students and practitioners
- evaluate educational preparation for multiprofessional teamwork through an assessment of the processes and outcomes of shared learning and teaching with other professionals, including social workers.

We drew on a variety of sources of data, including the questionnaire survey already discussed; a survey of the documentation and analysis of the 163 Board-approved programmes providing pre- and post-registration education for learning disability nurses, and a more detailed study of a sample of programmes including interviews with programme leaders, focus groups with students and interviews with employers.

1.6.1 A survey of programmes: an analysis of programme documentation

Previous experience (Alaszewski et al., 2000) indicated that not only was there a practical problem of accessing programme documentation from programme providers, but that many felt they received too many requests for research access. We also found that when programme directors were asked to provide general documentation, they sent differing types of documents. To reduce overload and ensure consistency of material, we decided to survey the documentation held at the four Board regional offices for purposes of programme approval. Prior approval was sought from each educational institution that had submitted documentation. All the institutions contacted agreed to allow us access to the material with the exception of one, which was in the process of reviewing its documentation.

A total of 163 programmes were analysed from 49 institutions (Table 1.2) – the majority of programmes at both pre- and post-registration level with the exception of second to first level conversion programmes and non-Board approved programmes. Although these would have been valuable, time constraints meant that we were unable to include them.

Pre-registration

- Diploma in Higher Education programmes
- Shortened programmes for nurses on other parts of the Professional Register
- Degree/Part 14
- Joint Learning Disability Nursing/Social Work Diplomas
- Joint Learning Disability Nursing/Social Work Degrees

Post-registration

- Specialist practitioner degrees
- N02 – Understanding and working with challenging behaviour
- N45 – Nursing care of the individual with epilepsy
- N47 – The care and management of people with learning disabilities who present with mental health problems
- N65 – The physical, sexual and psychological abuse of adults with learning disabilities
- 769 – Coping with violence and aggression: effective prevention and management techniques for practitioners (stage 2)
- 770 – Nursing within controlled environments
- 807 – Nursing people with a mental handicap/learning difficulty in the community
- 936 – Developments in mental handicap nursing
- 937 – Behaviour modification in mental handicap nursing
- 939 – Care of people with mental handicap in community residential and day services
- 956 – Coping with violence and aggression: effective prevention and management techniques for practitioners
- 958 – Care of mentally handicapped children in residential settings
- A22 – Advancing skills in managing change in services for people with a mental handicap
- A54 – Mental illness in people with learning disabilities
- A62 – People with learning disabilities, challenging behaviour and mental health problems
- A74 – Training the trainers – control and restraint techniques

Table 1.2: Classification of programmes whose documentation was examined

A number of themes were explored during our analysis of the content of programme documentation:

- aims and objectives of the programme
- learning outcomes – skills, knowledge and attitudes taught
- teaching methods
- methods of assessment
- evidence of shared learning
- values taught
- teaching and learning philosophy
- user/carer involvement in programme design and delivery
- preparation for multiprofessional, multi-agency work
- organisation and assessment of placements.

The material relating to each programme was read thoroughly and information relating to the above themes was noted. For ease of analysis a grid was devised which enabled comparisons of the knowledge, skills, attitudes, and methods of teaching and assessment for each programme

to be made. This made it possible to identify common areas of teaching and made the differences between the programmes more apparent. With reference to the Board's 10 key outcomes and the UKCC's Rule 18A we established the 'core' learning outcomes of the programmes and identified the individual aspects of each programme. We were able to determine exactly what students are taught according to the documentation submitted to the Board. We were aware that this information might not accurately reflect the realities of the programme so we moved on to the next stages in order to develop a broader picture of the realities of nurse education.

1.6.2 A detailed study of a sample of programmes

1.6.2.1 Sampling

Following the content analysis, 12 programmes were chosen for more detailed analysis. These were selected to represent both pre- and post-registration programmes, different types of programmes and different geographical locations. Where possible they were also selected on the basis of distinguishing features – such as distinctive organisation, linkage between health and social care and special elements to prepare nurses for multiprofessional, multi-agency teamwork. In the case of short post-registration programmes we were more restricted in our selection since we were confined to those in progress at the time of our analysis (Table 1.3).

To build up a more accurate picture of current nurse education we arranged to visit those institutions whose programmes were selected for further analysis. We interviewed programme leaders and conducted focus groups with students. Later, we approached the main employers of students from the programmes to arrange interviews so that we could gather a rounded view of the current system of nurse education.

Type of programme	No. analysed
Pre-registration	
• DipHE Learning Disability Nursing	3
• Diploma Learning Disability Nursing and Diploma in Social Work	1
• Degree in Learning Disability Nursing with a Diploma in Social Work	1
• Degree in Learning Disability Nursing	1
• Shortened Diploma in Learning Disability Nursing for Nurses on other parts of the Professional Register	1
Post-registration	
• Specialist practitioner degree	1
• N02 – Understanding and working with challenging behaviour	1
• N47 – The care and management of people with learning disabilities who present with mental health problems	1
• Caring for people with learning disabilities and mental health needs	1
• 770 – Nursing within controlled environments	1

Table 1.3: Programmes included in the more detailed study

1.6.2.2 Interviews with programme leaders

Leaders of the 12 programmes were approached by telephone and the aims of the project were outlined. They were key participants in this phase of the research since they were interviewed themselves, arranged most of the focus groups and gave the research team contact names of students' employers. All the institutions we approached were keen to participate in the project.

Individual members of the research team visited each institution and met the programme leaders. Interviews were conducted on a one-to-one basis, with the exception of one a programme leader who was accompanied by a lecturer in learning disability nursing.

The aims and objectives of the project were outlined at several stages prior to the interview, the main aim of which was to examine the nurses' preparation for practice and how this was achieved through the programmes. The interviews examined several areas, including:

- programme design and development
- curriculum content
- preparation of learning disability nurses for practice
- strengths and weaknesses of the programme
- updating.

Each interview had 18 fairly broad, open questions intended to encourage reflection and discussion. They lasted between 35 and 75 minutes, were tape-recorded, and the interviewer took notes during the interviews. All recordings were transcribed and later deconstructed and analysed, and emerging themes recorded.

1.6.2.3 Focus groups with students

The programme leaders were asked to facilitate focus groups with current students to enable the research team to access their views. We attempted to gather a selection of students representing the different years or stages of the programme, although this was not always possible. We found that students in the later stages of the programme were often in the best position to comment on their preparation for practice; those in the earlier stages often felt it was too soon for them to comment.

The number of students included in the focus groups depended upon the number currently undertaking the programme (Table 1.4). In most cases all students in the final year of the pre-registration programmes and most of those in the post-registration programmes under analysis took part.

Discussion amongst the students was encouraged and the researchers used a number of questions as prompts and to guide the discussion. The focus groups explored similar issues to those examined with the programme leaders. A number of themes were addressed:

- aims and objectives of the programme
- preparation for practice
- strengths and weaknesses of the programme
- curriculum.

The focus groups were recorded and transcribed. The team studied the transcripts to identify emerging themes. Many issues raised by students on one programme were echoed by students on others. It was therefore not difficult to analyse the material from the transcripts.

Institution	Programme	Prog. leader	Students	Employers	Diaries
1	DipHE Learning Disability Nursing	1	12 (all 3rd yr)		2
2	DipHE Learning Disability Nursing	1	4 (all 3rd yr)		
3	DipHE Learning Disability Nursing	1	10 (all 3rd yr)		3
4	Degree – Learning Disability and Social Work	2	4 (all 3rd yr)	1 NHS 1 social services	
5	Diploma – Learning Disability and Social Work	1	13 (all 3rd yr)	1 NHS 1 social services	
6	Degree Learning Disability Nursing with Registration on Part 14	1	3 (2 3rd yr, 1 1st yr)	1 charitable organisation	
7	Shortened programme for those already on other parts of the Professional Register	1	1 (end of programme)	None available. – first student on the programme	1
8	Post-registration Specialist Practitioner Degree	1	4 (all 1st yr)	1 NHS	2
9	N02 – Understanding and working with challenging behaviour	1			
10	N47 – The care and management of people with learning disabilities who present with mental health problems	1			
11	Caring for people with learning disabilities and mental health needs	1	6	1 NHS	
12	770 – Nursing within controlled environments				

Table 1.4: Student participants in the interviews and diaries

1.6.2.4 Interviews with employers

Programme leaders were asked to identify the main sources of employment for students who had successfully completed the programme. In each case several contact names were given. We selected a minimum of one employer for each programme and contacted them to arrange an interview. Since many employers held similar views on nurse education we felt that the seven interviewed adequately represented employers' views.

Interviews took place over the telephone, as we found that this best suited the employers. They covered a number of areas, including:

- knowledge of programme content
- their involvement in programme development and delivery
- whether the programme prepared students for practice
- any additional training they gave newly-qualified nurses upon employment.

Each interview comprised 12 open questions with the aim of encouraging reflection and discussion. Two additional questions invited the interviewee to comment on any aspect of learning disability nursing they chose.

The interviews lasted between 35 and 90 minutes; all were tape-recorded and the interviewer took notes. The emerging themes and views were noted and we were able to identify significant findings from the interviews with employers.

1.6.2.5 Diaries: using students as observers

We were aware that interviews could only provide a 'snapshot' of the educational process and it was important to use such data to access important aspects of the educational process such as the development of skills and competencies in practice. These can only fully be accessed through observation, but this was not feasible. We therefore invited students to act as observers of the learning process by completing a diary recording their observations. All students who took part in the focus groups were invited to participate and initially all agreed. They were briefed prior to completing the diaries and supplementary information was attached to the diaries. We received eight diaries (Table 1.4); although all students agreed to complete them, many later said that they could not spare the time.

1.7 Summary and comment

The Board commissioned studies of aspects of nurse education in England and our own study forms part of this expanding body of work. We were concerned to develop the best features of our own and other Board-commissioned research, and therefore set our study within an explicit methodological framework starting with the concept of quality.

As with many key concepts, there are alternative approaches to quality. It can be seen in terms of gold standards, predefined standards that can be used as a yardstick for measurement. While some 'benchmarking' is currently taking place we did not feel that this approach was appropriate for our study. The rapid recent changes in the nature and pattern of service delivery, the absence of agreed benchmarks and the importance of user and carer perspectives meant that a more open approach was required. We decided to use 'fitness for purpose', because it underpinned the methodology used by the QAA and Board to evaluate the overall provision of nurse education, and enabled us to explore the nature of current learning disability nurse practice and evaluate the extent to which educational provision prepared nurses for this.

We divided our research into two parts; the first concentrated mainly on the nature of contemporary nursing practice, the second on the appropriateness of nurse education for this practice. Our analysis of contemporary practice started with an analysis of secondary sources to map the development of learning disability practice and nursing. We complemented this with a questionnaire survey of learning disability nurses. This was in turn complemented by a series of case studies that provided detailed information on the roles and activities of learning disability nurses, and focus groups with users and carers that enabled us to access their views.

The second part of our research explored the nature of educational provision and the extent to which it prepared nurses for practice. We drew on those parts of the questionnaire that examined nurses' educational experiences and identified areas in which they felt their education could be developed. These data were complemented with a survey of programme documentation held by the Board, enabling us to examine the ways in which programmes defined their objectives and how they intended to achieve this. Case studies of 12 programmes drew on individual and focus group interviews with programme leaders, students and employers plus student diaries, and we were able to draw on the focus groups for user and carer perspectives.

2.1 Introduction

This chapter traces the development of services for people with learning disabilities and the associated development of learning disability nursing. We have examined three periods in which significant developments occurred: the 1850s to the 1920s; the 1950s to the 1960s; and the 1970s to 2000.

The history of learning disability services has been characterised by periods of slow change followed by bursts of rapid change (Swann, 1997). The development of services is linked to the prevailing attitudes of the era. As the Jay Committee (1979: para. 19) pointed out, policies on 'mental handicap' have been *'subject to regular and radical alteration, reflecting the ideas, motives and ideologies of the time; prejudice on the other hand remained constant'.*

People with learning disabilities have been treated with suspicion (Gates, 1997a), as a threat to society (Alaszewski, 1988), with pity, fear and hostility (Norman et al., 1997), and as a burden to society (Race, 1995b). In recent years there has been recognition that they should be treated in the same way as other citizens, having the same rights to opportunities (DoH, 1996a) and valued lifestyles.

We will examine each period in relation to three issues: policies of the time – including assumptions about the causes and nature of learning disabilities; services; and the role of the specialist nurse, and how prevailing attitudes and beliefs have influenced policy. The role of nurses will be explored in relation to each era and particular attention will be paid to the skills demanded in the light of recent changes in service provision.

2.2 Initial awareness and development of provision: late 19th and early 20th century

2.2.1 Attitudes and beliefs

Awareness of the distinctiveness of people with learning disabilities can be traced back to the 13th century, when they were referred to using everyday language such as 'fool', 'natural fool' and 'idiot' (Neugebauer, 1996). However, little official attention was paid to them; prior to the late 19th century *'idiots and imbeciles were not recognised by the reformers as a distinctive group with special needs'* (Alaszewski, 1986: 14).

A number of social and political changes highlighted the position of people with learning disabilities. Changes in working practices placed a new emphasis on learning and people's ability to cope with new technological and commercial processes (Race, 1995b). A new emphasis on education was enshrined in legislation such as the 1870 Elementary Education Act and the development of compulsory education. Some children with learning disabilities began to stand out as being *'educationally and practically of low competence'* (Race, 1995b: 46).

In the mid 19th century educationalists saw such children as a challenge and were confident that they could educate them. Itard and Seguin, key figures in the Sensationism movement, assumed *'that to train the senses was to train the mind and that deficiencies in the latter could be corrected by making up presumed deficiencies in sense knowledge and sense power'* (O'Connor and Tizard, 1956: 2).

However, in the late 19th century, optimism was increasingly replaced by pessimism. It was thought that children with 'mental deficiency' could not be educated to any valuable extent and that *'they would always be a drain on society'* (Race 1995b: 47). According to Tizard (1958) two events contributed to this change in attitudes and set the development of learning

disability services back by 50 years: the development of a standardised instrument to measure intelligence, and the emergence of the eugenics movement.

At the start of the 20th century Alfred Binet and Victor Simon produced a 'scientific' method of measuring intelligence, designed to separate children who were *'congenitally and mentally retarded from those who were environmentally disadvantaged; the former were to be viewed and treated as ineducable'* (Gates, 1997b: 5). Their method implied that intelligence is inherited and therefore could not be developed by education (O'Connor and Tizard, 1956); this belief was fostered by the emerging eugenic ideas (Race, 1995b).

According to Farmer et al. (1993) eugenicists feared that class conflict would spill over into violence and civil war. Class conflicts developed within most European states, with heightened internal conflict (trade unions and socialist parties) and external conflict (economic rivalry and imperial tension). Internal conflict gave rise to fears about the development of an underclass, which was reinforced by concerns that the population could not sustain the inevitable international conflict (Alaszewski, 1988). In a popular misinterpretation of Social Darwinism, it was believed that the fittest state would survive and dominate others and, as such, mentally defective people were seen as a serious social threat (Alaszewski, 1988).

By 1910 the ideas of the eugenics movement were widely accepted (Alaszewski, 1988). Francis Galton, a key geneticist, believed that Mendel's law applied to intelligence as well as physical characteristics: undesirable characteristics would be passed on through breeding. Tredgold (1909) believed that the 'feeble-minded' had more children than the national average and posed further dangers by breeding with 'healthy' members of the community.

A number of case studies purported to show the links between feeble-mindedness and social deviance (Baly, 1995). Tredgold (1909) contended that society needed to be protected from the feeble-minded, and in turn they needed protecting from certain sections of society. The eugenics movement continued to influence official policy until the end of World War Two, after which the Nazis' actions had destroyed much of its credibility (Alaszewski, 1988).

2.2.2 Terminology

The Jay Committee (1979) identified one of the earliest references to people with learning disabilities as being a 14th century statute which distinguished 'born fools' from 'lunatics' for the purposes of property law. The 1325 statute *De Praerogativa Regis* (cited in Neugebauer, 1995) dealt differently with the lands of 'natural fools or idiots' – those born with learning disabilities – and 'lunatics' – those of unsound mind. Although this distinction between 'idiots' and 'lunatics' existed in property law, it was a long time before they were distinguished in medico-legal terms (Digby, 1995). Indeed, the term 'lunacy' did not exclude mental disability until the 20th century (Digby, 1995).

Terminology used to describe people with learning disabilities in the 17th century included 'idiot', 'stupid', 'innocent', 'natural' (Andrews, 1995), 'simple' (Rushton, 1995) and 'blockheaded' (Goodey, 1995). Such terms tended to be used in legal and other official language.

One of the developments of the early 20th century was a more specialised terminology (Walmsley et al., 1999), such as Down's syndrome. In theory the terminology was 'neutral' and 'technical', but in practice it was negative and value-laden. The 1904 Royal Commission recommended the general term 'mental defect' be used *'to cover all forms of mental disorder, including mental illness'* (Race, 1995a: 15). Four grades of mental deficiency were identified by the 1913 Mental Deficiency Act: idiots, imbeciles, feeble-minded persons and moral defectives; these categories remained in place for almost 50 years (Race, 1995a).

2.2.3 Policy development

Initial policy development reflected optimism about the educability of people with learning disabilities. After the 1889 Royal Commission identified the category of 'feeble-minded'

children (Alaszewski 1988), the Board of Education set up a committee to investigate their education. The committee recommended segregation for the purpose of education (Alaszewski, 1988).

'Mental defect might have remained an "educational problem", if the identification of defectives had not coincided with a moral panic about the quality of the population' (Alaszewski, 1988: 4); policy-makers had to respond to growing public pressure for something to be done about people with learning disabilities. A Royal Commission was appointed in 1904 to investigate the 'problem'; heavily influenced by the emerging genetic movement, the Commission accepted the principles of segregation (Bannerman and Lindsay, 1993), and promoted the development of institutions.

The 1913 Mental Deficiency Act was based on the recommendations of the Royal Commission and was made up of three main elements:

- the identification of people with learning disabilities
- their supervision in the community where possible
- their segregation where this was considered necessary.

The Act established a legal category of mental deficiency and introduced compulsory certification; people with severe learning disabilities could be placed in institutions, and had no control over the proceedings. It also advocated the creation of specialist facilities and formalised community-based care for some people by systems of guardianship, license from institutional care and statutory and voluntary supervision. Although its implementation was delayed by the 1914-1918 war, the provisions of the Act formed the basic framework of services until 1959.

2.2.4 Implications for services

Prior to the mid 19th century, institutions existed only to confine persons so sick or disabled that no household could care for them (Rothman, 1971). In the middle of the century institutions became *'the preferred solution to the problems of poverty, crime, delinquency, and insanity'* (Rothman, 1971: xiii). For most of the century the workhouse was the dominant institution for people with learning disabilities. Specialist asylums were still a rarity – in 1881 of nearly 30,000 'idiots' in public institutions only 3% were in specialist asylums (Brigham, 2000).

At the end of the 19th century eugenicists' beliefs had a powerful influence (Bannerman and Lindsay, 1993). There was a rapid growth in the number of institutions, or colonies, built some distance from urban centres with the aim of protecting society (McConkey, 1996). Admission was considered to be in the 'best interests' of those admitted (DHSS, 1971) as it was believed that people with learning disabilities would be *'far happier ... amid companions like themselves than in the outside world'* (Tredgold, 1909: 104).

2.2.5 The development of the nursing role

The history of learning disability nursing is underdeveloped and undertheorised, unlike that of general nursing (Mitchell, 1998d). However, prior to the growth of institutions, parish nurses provided some assistance in the care of people with learning disabilities – where families could afford it. Although some parish nurses specialised in caring for people with learning disabilities, there was little evidence of a specialist workforce (Mitchell, 1998d).

With the development of institutions came the demand for a new workforce. Asylum staff were initially known as 'keepers', then 'attendants' before being classed as nurses. Management was the responsibility of medical superintendents, and conditions were such that the superintendents rarely succeeded in recruiting *'intelligent, kind, industrious and creative attendants'* (Dingwall et al., 1988: 127). Instead they had to employ *'ignorant and heavy-handed disciplinarians who were unemployable elsewhere'* (Dingwall et al., 1988: 127).

Prior to the 1919 Nurses' Registration Act, the term 'nurse' was used freely to describe all women involved in physical care. According to Mitchell (1998d: 14), this was one reason why trained hospital nurses became *'the obvious profession from which to draw staff to work with people with learning disabilities'*.

Until 1890 there was no national training scheme for asylum staff (Benicki and Leslie, 1983). Individual asylums set their own objectives and standards for training (Jay Committee, 1979), which were usually directed towards 'mental' nursing.

A number of suggestions have been proposed to account for the development of training for people caring for those with learning disabilities. Dingwall et al. (1988) argued that towards the end of the 19th century, doctors attempted to find an organic basis for learning disabilities in the hope of identifying remedies and thus needed more skilled assistants; Nolan (1993) argued that trained nurses improved doctors' prestige. Mitchell (1998b) argued that nurse training was created by medical superintendents as a means of controlling the workforce. Lacking a clear 'medical' role within institutions, doctors relied on controlling the workforce to ensure their influence within the growing number of institutions (Mitchell, 1998d).

Until 1919 learning disability nursing was treated as part of nursing people with mental illness, and it was believed that people with mental illness and those with learning disabilities could be cared for by the same staff in the same institutions (Jay, 1979). In 1919 the difference between mental health and learning disability nursing was formally accepted (Mitchell, 1998c); the first nursing certificate in 'mental deficiency' was awarded and a separate register introduced. Attendants became the first nursing branch to *'acquire a relatively uniform system of training and examination and a register of certified practitioners'* (Dingwall et al., 1988: 129).

Although learning disability nursing had been formally differentiated it was not accorded equal status with other branches of nursing. The General Nursing Council (GNC) failed to accept it as a valid or 'full' branch because they were not seen as carers of the sick, but as educators, and therefore not 'real' nurses (Mitchell, 1998a; 1998c). The GNC's reluctance to include learning disability nursing in the profession was counterbalanced by the medical superintendents, who were keen to promote and support their role and status (Mitchell, 1998d).

2.3 Reform and reconstruction: the 1950s and 1960s

2.3.1 Attitudes and beliefs

At the start of the Second World War, 46,054 people with learning disabilities lived in institutions (Walmsley et al., 1999). Following the war there was a major shift in attitudes. Rather than being the solution, institutions came to be seen as the problem. They were characterised as *'places of profound humiliation, which stripped individuals of human worth and dignity'* (Felce, 1996). Conditions were exposed as being poor and they were also identified as *'places of restriction of civil liberty and rights in the interests of society'* (Felce, 1996). The rise of the civil rights movements emphasised that all human beings are *'worthy of the same dignity and respect as others'* (Whitehead, 1993: 50-51).

In the 1940s the architects of the welfare state wanted to build a universal welfare system. In the process of implementing this system, policy-makers 'rediscovered' people with learning disabilities, many of whom had been 'put away' in institutions in the 1920s and 1930s.

By the 1950s the eugenicists' views were no longer scientifically tenable, partly due to the re-emergence of a cautious optimism about the educability of people with learning disabilities. Their segregation *'on the grounds of preventing genetic pollution became redundant'* (Felce, 1996). It was also related to a number of critical inquiries in the 1950s and 1960s of the perceived inadequacies of the existing provision (Race, 1995b). Researchers began to demonstrate that, given the right environment, people with learning disabilities could be useful to society and could respond to training.

2.3.2 Terminology

Between the wars little systematic study was undertaken into the problems of classification of mental deficiency (Race, 1995a). Within the institutions, the medical superintendent's interpretation was usually enough to justify continued certification, and the looseness of terminology in the 1913 Act meant that practically any opinion could be justified by a patient's behaviour (Race, 1995a). In the 1950s and 1960s some experts began to challenge the view that mental deficiency was an objective scientific category that could easily be identified (Alaszewski, 1988). Mercer (1973: 33) observed that *'an individual is socialised to play the role of mental retardate once he has been placed in that role by the social system'.*

A growing sensitivity emerged in respect of the terminology used to refer to people with learning disabilities, and a search began for a more accurate and acceptable term. The 1957 Royal Commission recommended the re-classification of mental disorder, and the 1959 Mental Health Act replaced the terminology of the 1913 Mental Deficiency Act with the newly-identified categories of 'mental subnormality', and 'severe mental subnormality' (Gates, 1997b). At the same time the World Health Organization used the term 'mental retardation', later dividing it into 'mild', 'moderate', 'severe', and 'profound' (Race, 1995a). However, the terms 'subnormal' and 'defective' still suggested that people with learning disabilities were less than human. Gradually mental handicap emerged as a less pejorative term.

2.3.3 Policy development

Post-war years were a period of reappraisal of policies for people with learning disabilities. The decline of eugenics and the rise of civil rights forced policy-makers to readdress the care and classification of people with learning disabilities.

The institutional system reached its peak of around 60,000 beds at the end of the 1960s (Alaszewski, 1988), when there were few alternatives to hospital care (Race, 1995b). In the post-war period policies changed direction in line with the beliefs that people with learning disabilities could be better cared for and achieve greater social and economic independence in the community rather than in hospitals (Bone et al., 1972). It was recognised that the existing services and systems were inadequate and that improvement required a new pattern of services rather than reform of existing ones (Felce, 1996). The 1950s and the 1960s could perhaps be described as the transitional stage whereby service provision and resources started to move away from the institutions towards care provided in more normal settings.

In 1957 a Royal Commission whose terms of reference included the investigation of *'the existing methods of dealing with idiots and epileptics, and with imbeciles, feeble minded or defective persons not certified under the lunacy laws'* published its recommendations. The Commission placed a new emphasis on community care and the removal of segregation (DHSS, 1971). It also recommended the development of local authority services to run alongside institutions (Alaszewski, 1988). The institutions were to continue to care for people who required long-term nursing and medical support, whilst parallel services were to develop for those who could be cared for in the community.

The 1959 Mental Health Act changed the pattern of hospital care – legal detention was to be a last resort rather than the basis of virtually all treatment. It also gave local authorities responsibility for providing a range of community services including residential accommodation (DHSS, 1971). Gates (1997b: 12) pointed out that the Act *'reflected a fundamental shift in the attitudes of legislators, if not society as well'.*

However, the 1959 Act was unpopular with many of those concerned with people with learning disabilities because large hospitals remained the alternative to keeping people at home (Malin et al., 1980). During the 1960s debates took place as to the best solution to the problems of the institutions, while some attempted to divide people with learning disabilities into groups and identify the distinctive needs of each group (Tizard, 1964; Dutton, 1963).

A number of inquiries during the 1960s and 1970s exposed professional neglect and suffering among people were living in institutions (Norman and Redfern, 1997). In response there were a number of broader policy investigations, including the Jay Committee (1979), the Briggs Committee (DHSS, 1972) and publication of the influential *Better Services for the Mentally Handicapped* White Paper (DHSS, 1971).

Following a series of hospital scandals (Martin, 1984) in 1969 Richard Crossman, the Secretary of State for Social Services commissioned a study to examine the services for, and the needs of, people with learning disabilities. The resulting White Paper (DHSS, 1971) was the first major policy review since 1929 (Alaszewski, 1983). In response to the growing concern about large institutions, it criticised the custodial tradition of care, emphasised the importance of education, and showed that the potential for development was about acknowledging the limits of each person with learning disabilities.

This White Paper set the framework for a major shift in the pattern of services. It considered that people with learning disabilities should live at home with their families – or if that was not possible then the alternative should be as 'homelike' as possible (DHSS, 1971). Although the policy of community care can be traced back to the Royal Commission of 1957, the 1971 White Paper observed that development in community care since 1957 had been limited (DHSS, 1971).

2.3.4 Implications for services

Although policy statements of the 1950s and 1960s outlined proposals for a move away from hospital care to community-based services and support, it was almost 40 years later that the first major hospital closed. Hospital, or institutional care, was intended to be for those requiring extra support, whilst community residences were to be developed for other people with learning disabilities. In reality the majority of people needing support remained in hospitals, not least because there were few alternatives (Malin et al., 1980). In England and Wales in 1969, 58,850 beds in hospitals or hospital units were provided for people with learning disabilities, compared with only 4,900 places in community residential care (DHSS, 1971).

Service developments in the 1950s and 1960s included hostels, voluntary homes, and training centres within the community. Hostels were defined as *'residential accommodation in small units'* (Race, 1995b). The definition of 'small' varied so that in some cases the hostels appeared as slightly smaller versions of the large hospitals. Hostels, however, were viewed by researchers as an improvement on the patterns of care given in hospitals, giving more individualised care, offering greater flexibility, and enabling the development of personal relationships (Malin et al., 1980). The quality of voluntary sector provision also varied greatly. Training centres were established in response to the renewed optimism concerning the educability of people with learning disabilities; these enabled 'imbecile' children and adults to *'do handiwork, have games and music, and learn useful social and personal skills'* (Tizard and Grad, 1961: 4).

2.3.5 The changing nursing role

Following initial excitement and enthusiasm for institutions in the 1920s and 1930s, when they felt in the forefront of development, many nurses considered they were left with the *'burden of care on behalf of a seemingly uncaring community'* (Birchenhall, 1982: 134). So when the institutions became the focus of a number of investigations in the 1960s, nurses felt resentful of the sudden interest in places where they had been left to *'hold the fort'*. The development of the multiprofessional team to provide care and support in the community was initially seen by many nurses as unnecessary, even insulting, and also made some feel insecure and marginalised (Birchenhall, 1982).

As the hospitals began to close, the role of the learning disability nurse was subject to increasing scrutiny. Norman and Redfern (1997) argued that in the early days of community care learning disability nurses were left to care for those in hospital, for whom it was believed

that community care was unsuitable. With the transfer of emphasis to the community came job insecurity for specialist nurses (Sines, 1993), and hospital staff faced anxieties about *'a possible loss of identity, commitment and professional standing'* (Jay Committee, 1979: 151).

2.4 Normalisation and beyond

2.4.1 Attitudes and beliefs

Attitudes towards people with learning disabilities have changed a great deal since the 1970s, when they tended to be seen as unfortunate victims attracting sympathy and even pity (DHSS, 1971). Since then there has been movement towards a more positive outlook. They are no longer viewed as objects of charity but as people in their own right. In a similar vein, they are now seen as being entitled to the same rights as others. Like other people, those with learning disabilities have to accept the risks and insecurity of ordinary life.

Terms such as 'participation', 'consumerism', 'empowerment', 'advocacy' and 'enabling' are now frequently used in relation to people with learning disabilities. Empowerment, according to Simons (1995: 170), *'implies a process in which people with learning difficulties take some control over what is happening'*. People with learning disabilities are becoming more involved in making decisions about their own lives, and self-advocacy in particular has been called *'the major development affecting services for people with learning disabilities'* (Race, 1995b: 71).

In recent years there has been a growing emphasis on consulting service users about factors which affect them, such as their service needs and life generally (Malin, 1995). The rise of the self-advocacy movement People First was an important development in the 1980s (Malin, 1995), as was the Campaign for People with a Mental Handicap – later renamed Values into Action. Such groups led to community care being redefined not in terms of how best to close hospitals but how policy can best respond to the needs of individuals with learning disabilities (Malin, 1995: 2). Legislation such as the Disability Discrimination Act 1995 has broadened the debate to that of rights and citizenship. The disability movement has begun to offer the possibility of an identity of 'disability' to all disabled people including those with learning disabilities.

People with learning disabilities are no longer perceived as a social problem, a burden or a threat to society. The new emphasis is on their empowerment, integration and inclusion in society. The general belief now is that *'all people should have equal chances in life regardless of their race, sex or creed'* (Bannerman and Lindsay, 1993: 29). However people with learning disabilities themselves often challenge this rhetoric, presenting continuing evidence of discrimination, abuse and exclusion.

2.4.2 Terminology

There has been a major debate on terminology, though even today some are still confused by the difference between mental illness and learning disability (Race, 1995a).

During the 1970s the term 'mental handicap' became used more widely and was usually divided into either 'mild' or 'severe' (Race, 1995a). The 1971 White Paper used the term mental handicap *'in preference to any of the alternative terms because this helps to emphasise that our attitude should be the same as to other types of handicap'* (DHSS, 1971: para. 4). Clarke (1986) preferred the term as it carries the implication that a handicapped person can be helped to overcome the handicap. According to Race (1995a: 22), the term *'grew in parallel with the development of a greater variety of services and the greater involvement of non-medical staff in the care of people with learning disabilities'*. The development of the concept of normalisation created debates about the effect of labelling (Race, 1995a) which resulted in the use of a number of alternative terms including 'developmental disability', 'developmental handicap' and 'special needs' (Race, 1995a).

The 1983 Mental Health Act introduced the classifications of 'mental impairment' and 'severe mental impairment' (Gates, 1997b). Terminology became increasingly affected by greater sensitivity and the growing move towards enablement (Digby, 1995). The term 'mental handicap' came to be viewed as prejudicial and as a term of abuse (Farmer et al., 1993) especially as the term 'handicap' carried with it 19th century notions of charity. Many people labelled as mentally handicapped rejected the label as inaccurate and unpleasant (Puddicombe, 1988) and preferred to be known as people with learning difficulties; professionals similarly chose this term or learning disability (Open University, 1998). A reflection of the changing acceptability of terminology can be seen in the way in which the journal *Disability, Handicap and Society* in 1994 changed its name to *Disability and Society*, and journals in the area of learning disability have also revised their terminology.

The term 'learning disability' evolved in the early 1990s to describe people with *'significant developmental delay that results in arrested or incomplete achievement of the 'normal' milestones of human development. These relate to intellectual, emotional, spiritual and social aspects of development'* (Gates, 1997b: 7). In 1991, the Secretary of State for Health, Stephen Dorrell, speaking at a MENCAP conference confirmed the official change in terminology from 'the mentally handicapped' to 'people with learning disabilities' (MHNA, 1991). He argued that it reflected a change in attitudes, noting that the change *'should reflect our commitment to thinking of people with learning disabilities as individuals in their own right – people are entitled to assistance in overcoming their disability for one simple reason – they are citizens; they are full members of our society'* (MHNA, 1991: 17).

2.4.3 Policy development

The policies of the past 30 years have built on the foundations of the 1950s and 1960s. Rather than the 'twin-track' mechanisms of community care for the more able and institutions for the less able, policies began the move towards community or non-hospital care for almost all people with learning disabilities.

The reasons for this are not entirely clear or evidence-based, but appear to be due, in part, to changing attitudes among the public and policy-makers. People with learning disabilities have come to be seen as being entitled to the same rights, responsibilities and opportunities as any other member of the community. Policy emphasis shifted towards their social inclusion and this meant entitlement to the same rights of access to services as anyone else.

Community care policies have been strongly influenced by the movement towards social inclusion, the acknowledgement of the rights of people with learning disabilities, and the need for individualised care. The Jay Committee worked from three principles:

> *'(a) Mentally handicapped people have a right to enjoy normal patterns of life within the community.*
>
> *(b) Mentally handicapped people have a right to be treated as individuals.*
>
> *(c) Mentally handicapped people will require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individuals.'*
>
> (Jay Committee, 1979: para. 89)

Living in the community is increasingly the reality for people with learning disabilities, as long as the concept of community is broad enough to encompass residential and nursing home care. While policy within health and social care was central to this move, an important development in 1980s policy was the extension of the benefits system (Booth et al., 1990). The introduction of benefits such as attendance allowance, mobility allowance, severe disablement allowance and so on were significant in helping people with learning disabilities to remain with family members or live in ordinary housing within the community.

The Department of Health (DoH) placed a greater emphasis on individualised care, and defined community care as *'providing the right level of intervention and support to enable people to achieve maximum independence and control over their own lives'* (DoH, 1989a: para. 2.2). The White Paper *Caring for People* set out the Government's proposals for improving community care (DoH, 1989a); taken together with *Working for Patients* (DoH, 1989b) it showed how the Government saw services developing, continuing the movement from institutions into the community. It advocated enabling people to live as independently as possible in their own homes, or 'homely' settings in the community, and envisaged that only those who required special medical or nursing care which cannot be met elsewhere would remain in hospital (DoH, 1989a).

This conception of community care was reinforced by the 1990 NHS and Community Care Act, which emphasised community and ordinary life principles. The Act created a series of new relationships between health and local authorities. Local authority social services departments (SSDs) were given the responsibility of providing and funding social care packages for people with a learning disability (Gates, 1997b). They were urged to work in close partnership with other agencies such as housing, further education, health and employment (DoH, 1991c).

The NHS and Community Care Act distinguished between health and social care for people living in the community but appointed local authorities the lead agents in the provision of care packages. This continued a number of debates about the most appropriate agency and/or model for care provision – a social or a health model (Gates, 1997b). Such debates have been apparent since the policy initiatives of the 1970s; Dingwall et al. (1988) argued that there was conflict between the nursing and social work professions over the ownership of territory in the new community facilities which were developing for people with learning disabilities.

Caring for People (DoH, 1989a) stated that community care was about health as well as social needs and pointed to the need for agencies to work together. The organisational mechanisms required for joint planning had been created in 1976 but a *'lack of co-operation caused by fundamental differences in values and approach between the lead agencies was evident'* (Norman and Redfern, 1997: 14).

In recent years there has been a gradual recognition of the need for packages of both health and social care for people with profound or complex needs. In 1996 the DoH (1996a) advocated the need for staff in the different areas to share their knowledge and skills to respond to the overlap between the roles of learning disability nurses and social workers. Different professions are exhorted to work together in order to provide both the social and health care packages required to enable people with learning disabilities to live as independently as possible in the community. The White Paper *Valuing People* sees partnership between agencies and professionals as the underpinning of services for people with learning disabilities (DoH, 2001). Iles (1998) argued that separating health care and social care does not benefit users of either service or help in the construction of seamless services.

The aims of community care policies were to provide individualised, personalised and ordinary living for, amongst others, people with learning disabilities, with accompanying savings from greater use of non-institutional settings, charges and targeting services on those most in need. The DoH provided a clear value framework for the new policies based on:

- *'A commitment to ensure that all users and carers enjoy the same rights of citizenship as everyone else in the community, offering an equal access to service provision, irrespective of gender, race or disability*
- *A respect for the independence of individuals and their right to self-determination and to take risks, minimising any restraint upon that freedom of action*
- *A regard for the privacy of the individual, intruding no more than necessary to achieve the agreed purpose and guaranteeing confidentiality*

- *An understanding of the **dignity and individuality** of every user and carer*
- *A quest, within the available resources, to maximise **individual choice** in the type of services on offer and the way in which those services are delivered*
- *A responsibility to provide services in a way that promotes the realisation of an **individual's aspirations and abilities** in all aspects of daily life.'* (emphases in the original, DoH, 1991a: 23)

The community care reforms also further involved the independent sector – voluntary, not-for-profit and private organisations. Policy-makers believed that using the market approach would lead to savings to the public purse plus greater choice for service users, and the independent sector has become the majority provider of residential services for people with learning disabilities.

2.4.4 Implications for services

The 1970s saw the beginning of the end of the old long-stay hospitals and many contracted in size; as the institutions began to close services developed within the community. Initially these were quite institutional; Bayley (1973) pointed out that in 1971 alternatives to hospital care were still state-run, segregated services in the form of large hostels and day centres. Children with learning disabilities were *'no longer excluded from education and adults stopped being automatically segregated from the mainstream of society'* (DoH, 1998: para. 1.2), though again segregated provision was established. Although there had been some changes in service provision in the 1970s they were not enormously significant.

The 1980s, by contrast, saw *'substantial growth in community care services, made possible by a significant increase in expenditure by central and local government'* (DoH, 1989a), albeit from a very low base. One significant but not universal development was the community mental handicap teams (CMHTs). Their main role was to *'promote community services through finding practical solutions in the community to the problems faced by families'* (Lockyer and Gilbert, 1995: 43). Some early teams were made up of two members – a specialist nurse and a specialist social worker (Simon, 1983), backed up by number of other disciplines including physiotherapists, occupational therapists, speech therapists. A multidisciplinary approach to meeting the needs of people with learning disabilities was seen as good practice. In contrast to the hospital model of care, community care has also required nurses to engage with and support family members or carers. The one-to-one relationship of nurse-to-patient was replaced with a more complex relationship in which the needs and interests of carers had to be considered. Some argued that there was an over-identification with carers; others that carers were still treated with suspicion and devalued (Malin et al., 1999).

In addition to service developments, a number of changes to the benefit system in the early 1980s were significant policy drivers for people with learning disabilities (Booth et al., 1990). Services aimed to enable people to live as normal a life as possible, achieve maximum possible independence and give them more say in how they live their lives (DoH, 1989a). Access to levels of income which enabled people to have some engagement with ordinary life were part of this commitment.

Services in the 1980s increasingly took the form of packages of social care for people living independently, or in small group homes or residential communities. The Government also aimed for services that:

- respond flexibly and sensitively to the needs of individuals and their carers
- allow a range of options for consumers
- intervene no more than is necessary to foster independence
- concentrate on those with the greatest needs (DoH, 1989a).

In the early 1990s, SSDs were made the main statutory agency for planning and arranging services for people with learning disabilities (DoH, 1998). However they were urged to work closely with health, education, employment and other agencies to provide the best possible services. These now aimed to be needs-led rather than expecting people to fit into whatever services were provided (Ayer, 1997), although high eligibility criteria meant that many people were not eligible for social care, especially if their levels of disability were considered to be moderate.

Care continued to move from hospitals to a range of alternative settings including group homes, hostels, lodgings and 'village communities'. Other options for people with learning disabilities included living alone, with their family, with other families, or in staffed houses. There was a rapid decline in the numbers living in hospitals; by 1998 only 3,000 people with learning disabilities in England still lived in hospitals (Brindle, 1998).

Today most people with learning disabilities live in ordinary housing, and fewer attend large adult training centres (ATCs) – smaller day centres are preferred (DoH, 1998). They are also more likely to spend time doing things as individuals rather than in groups (DoH, 1998). The lifestyles of many people with learning disabilities have changed a great deal over the past few decades. Services are expected to ensure that they have valued lifestyles, greater choice and control over their lives and are included more in the life of local communities (DoH, 1996a). The potential of Direct Payments is one example of this shift – these enable some people to purchase their own services directly, rather than relying on social services to purchase them on their behalf.

2.4.5 The changing role of nursing

In the 1970s there was considerable debate about the utility of a specialist nurse for people with learning disabilities. The Briggs Report (DHSS, 1972) and The Jay Report (Jay Committee, 1979) both considered that there was little justification for a specialty of nursing for the mentally handicapped.

The Jay Committee proposed that the Central Council for Education and Training in Social Work (CCETSW) should take responsibility for the training of residential care workers (Jay Committee, 1979). It envisaged a new class of 'care workers', and nursing was effectively invited to abandon the territory in favour of social work (Dingwall et al., 1988). The Committee's recommendations met with considerable opposition from nurses and their unions (Martin, 1984), and were quietly buried (Ryan and Thomas, 1987).

Since 1919 learning disability nurses have had to fight to have the value of their work recognised. Benicki and Leslie (1983) argued that they have not been as politically aware nor as articulate as nurses in other specialisms, but they are becoming increasingly assertive and confident in their ability (Sines, 1993). Since the Briggs Report recommended the ending of learning disability nursing (DHSS, 1972), Sines (1993) claimed that they have refocused their vision and emerged as a new and exciting specialism. However, many changes to the profession have not been through choice but engineered by outside forces and in response to social and political changes (Sines, 1993).

With the implementation of care management substantial change was inevitable for all staff, and left nurses having to develop new skills and methods of working (Norman and Redfern, 1997). The DoH (1991b) advocated inter-agency training, particularly where staff from different agencies need to work collaboratively and acquire similar or complementary skills.

Hospital closure was perceived as a threat to nurses; the environment to which they were accustomed was no longer the preferred model of provision. Care settings have further diversified, and opportunities for development in other settings have grown. Over the past decade learning disability nursing has changed in a number of ways. As care has moved away

from hospitals, learning disability nurses have had to move into a wide variety of settings – including respite facilities, day centres, special hospitals, social services departments (DoH, 1996a). As people with learning disabilities moved into the community, so did the nurses. The 1970s are credited with the development of the community learning disability nurse, though for many years previously hospital nurses had provided follow-up care for some discharged 'patients' (Elliott-Cannon, 1984).

The transition to community working was not always easy for learning disability nurses. They were expected to *'change the philosophical basis of their work, moving from a medical to an ordinary life basis'* in addition to their geographical base and sometimes their employing authority (*Community Living*, 1987: 7). However, they soon *'began to seize the opportunity to shift their role from the provision of custodial care in hospitals to domiciliary care and treatment in the community'* (Elliott-Cannon, 1984: 4).

The initial role of the community learning disability nurse was largely unclear. Sines (1985) noted that as community teams developed a unique role emerged for the community nurse, although there were several areas of overlap with other community professionals. McGrath (1991) added that community learning disability nurses would probably view their role as still developing. For example, learning disability nurses are moving into areas such as health promotion, counselling and parenting support, and developing specialist roles in areas such as challenging behaviour, epilepsy, and communications (Carlisle, 1997). They have been credited as having played a significant part in transforming services (DoH, 1996a).

Birchenhall et al. (1993) suggested that in addition to the traditional clinician and therapist role, learning disability nurses also act as educator/teacher, manager/leader, counsellor, and advocate. A DoH-commissioned project to examine the learning disability nurse's contribution to the care of people with learning disabilities identified a number of roles including needs assessment; health promotion; enablement and empowerment and using enhanced therapeutic skills (DoH, 1996a). Other roles include the provision of physical care; planning of developmental care regimens; and rehabilitation and remedial therapy (RCN, 1994). Birchenhall et al. (1993) defined three stages of the learning disability nurse's role: the primary stage relates to practical care; the secondary stage involves multi-agency working and the tertiary stage is concerned with *'the transference and integration of knowledge and skills'*.

Learning disability nurses have had to develop skills to work in multidisciplinary teams (DoH, 1996a), which have, since the early 1960s, been viewed as increasingly important in the provision of services (Ayer, 1997). *Caring for People* (DoH, 1989a) and the 1990 NHS and Community Care Act both promoted joint planning and working, and learning disability nurses have an important role in bringing the various services together and in providing support to, for example, housing associations and primary care teams (DoH, 1996a).

At the end of the 1980s some learning disability nurses felt that they were becoming sidelined as the social work profession took a more significant role in learning disability services (Carlisle, 1997). It is now argued that learning disability nurses have an established role and play a vital part in the provision of such services. In *Continuing the Commitment* (DoH, 1996a) and *Caring for People* (DoH, 1989a) the Government acknowledged their contribution to community care, their valuable skills and experience, and the fact that they are an important resource for health authorities, social services and voluntary bodies.

2.5 The development of policy and learning disability nursing practice

The final section of this chapter will discuss recent developments, drawing on our national survey of learning disability nurses. Many participants had worked through the major recent changes in policy and practice; less than 25% qualified in the 1990s and over 30% qualified before 1980 (Table 2.1); we will draw on evidence from our questionnaire to explore

 their perceptions of these changes. All quotation marks and emphasis in quotes were added by respondents themselves.

Year qualified	Percentage
1951-1955	0.1 %
1956-1960	0.4 %
1961-1965	1.5 %
1966-1970	3.7 %
1971-1975	10.1 %
1976-1980	21.2 %
1981-1985	19.7 %
1986-1990	20.7 %
1991-1995	15.3 %
1996-1999	7.1 %

Table 2.1: Year in which survey respondents qualified *(n = 730)*

Our respondents recognised that major changes had taken place to the nature of care for people with learning disabilities, and that this had had major implications for the nurse's role. The closure of long-stay hospitals and development of individualised care in 'ordinary life' settings meant they had had to adapt to significant changes in terms of management structures, the organisation and structure of care, the location of practice, and values and attitudes towards people with learning disabilities.

2.5.1 Terminology and values

The respondents recognised that a change in terminology underpinned a major shift in values and systems of care. Several used 'old fashioned' terminology, for example, mental subnormality or mental handicap, to emphasise the change in values. For instance one nurse who started training in 1955 made the following comment:

> *'When I started, the mentally handicapped "patients" were kept in "hospitals" and very little effort was made to develop their skills with a view to entering the community.'* (Resp. 32)

Another, who trained in the 1970s, commented on the linked changes in terminology to changes in values in the following way:

> *'My training concentrated on the caring role within an institution or hospital, and studying the "Principles and Practice of nursing people who were Mentally Subnormal" forgive the term. Too much time was spent studying anatomy and physiology and not behaviour. The emphasis is now on enabling and empowerment, a complete turnaround.'* (Resp. 651)

Respondents both recognised and endorsed the major changes in values. They considered that care was now geared towards the individual with:

> *'More emphasis on community care and integration. More emphasis on resident choice, decision making and advocacy. Caring/assisting the person rather than the disability. Involving people with a learning difficulty more – not just telling them what/how to do.'* (Resp. 115)

They contrasted this with the situation in the former institutional settings where:

'... the sheer weight of numbers and workload meant that "care" took precedence above individuality of the person cared for.' (Resp. 132)

Some respondents argued that staff:client ratios had improved, which led to more individualised care with fewer group activities and more time for individual choice. The emphasis had shifted to take account of what clients wanted – people with learning disabilities had more choice, more rights, more dignity and more privacy:

'The job has changed in that much more emphasis is placed on the rights of the clients. When I worked in a large hospital, I was mainly involved in custodial care and in providing basic needs i.e. food, clothing etc. Now my role is to provide the environment which will enable clients to develop their own living skills and their own sense of self worth ...' (Resp. 245)

The move into the community *'shifted the emphasis of the job away from "control/guard" to that of enablement and empowerment'* (Resp. 242). The rights and choices of people with learning disabilities as individuals had become policy imperatives and were key components of the learning disability nurse's role. As one nurse who began her career within an institution stated *'my job is now about making people feel valued – not about nursing or looking after people with learning disabilities'* (Resp. 651).

2.5.2 Changing policy

Respondents linked changes in terminology and values to changes in Government policy, especially the shift from custodial care within institutions to more personalised care in the community. All seemed to take these changes for granted. Indeed respondents only commented on the policy shift in terms of its negative or unforeseen consequences or impact on their own role. For example, one noted that:

'There is a definite difference between health care and social care. The Government policy in the last decade (10-15 years) has been emphasising heavily on social care. There are a number of service users who will continue to need health care within service provision. If the emphasis on social care remains exactly the way it is now then the Government/service user is heading towards a crisis which will show itself as "breakdown" of placements. Therefore we need to start looking at future service provision for the minority of service users who need a little bit more than social care.' (Resp. 653)

Respondents made more explicit reference to changes in Government policy, especially the development of internal markets in health care whose consequences were seen as overwhelmingly negative. One commented that *'Care is now a business – it is shameful'* (Resp. 644). While another stated that:

'Trusts are managed as businesses more and more and we are managers more than carers and trying to save money at the client's expense and detriment. My particular trust is mainly run by occupational therapists in managers' positions.' (Resp. 271)

Another respondent commented:

'Working as a nurse manager much of the job entails working within tight budgeting guidelines. The residents in certain situations have become commodities within the market place. More pressure on medical litigation fears and being aware that mistakes may have financial as well as ethical problems.' (Resp. 727)

2.5.3 Changing roles

Most respondents acknowledged that changes in policy and location of care had a major impact on the nature of learning disability nursing. However, 42.8% acknowledged that one of the main changes to the learning disability nurse's role has been in terms of the location of practice. Most cited the move into the community as the main change to their role. Nurses identified two contradictory trends: a greater emphasis on the learning disability nurse as a manager and a greater diversity of roles performed by learning disability nurses.

2.5.3.1 An increasing managerial role

Respondents indicated that their role was now much more managerial, with less emphasis on direct client contact and more on the management of care. One summarised the situation in the following way:

> *'Learning disability nurses now act as facilitators, care brokers, care co-ordinators, agents for monitoring quality, standards and outcomes and change merchants.'* (Resp. 314)

Several respondents linked this increase in managerial work to a perceived increase in bureaucracy and associated paperwork. As one explained:

> *'There is a lot more paperwork now. We have to justify our existence on paper. When I started the job we focused on caring – hands on caring – not writing all of the time about how we are going to do it. By the time we have written it all down we can't do it because we haven't got time. I never leave work on time now due to paperwork.'* (Resp. 503)

Nurses felt the amount of administrative work limited time for actual client care. Whilst client contact emerged as the most enjoyable or rewarding part of respondents' current posts it was not surprising that the bureaucracy which had taken them away from the clients emerged as the least favourite part.

A wider and more diversified role was particularly evident for nurses who were involved in the day-to-day management of residential and group homes. Their activities often included general housekeeping ranging from cooking and cleaning to gardening and maintenance work. Many felt strongly that this took them away from the service users and other important activities:

> *'Within my work area the job has changed from staff nurse with a therapeutic role to this role along with that of cook/cleaner as the cooks etc. were offered roles as care assistants and their jobs no longer existed. Nurses carry out these tasks in the guise of social role valorisation. However, in a respite unit for children, parents do not expect their children to cook and clean. Nurses do not therefore have time for therapies/social activities to as great an extent as before.'* (Resp. 462)

Nurses expressed concern that there was *'more emphasis on keeping nursing home[s] clean and safe than on interactions with residents'* (Resp. 334). The increase in activities which removed them from client contact was rarely welcomed by the nurses.

In some areas of work learning disability nurses felt that in order to maintain direct contact with clients and remain in the field they had to adopt a more specialised role. One suggested that:

> *'A higher proportion of nurses are required to specialise i.e. challenging behaviour as they feel the traditional role in social care/health care is being diminished.'* (Resp. 136)

In addition, some respondents felt that specialising in areas such as forensic or community nursing ensured that they would *'maintain their nurse status within a health care field'* (Resp. 197).

It appeared that learning disability nurses felt that if they did not specialise they would have fewer opportunities. According to some respondents, nurses also faced barriers because: *'it is of considered opinion that many clients do not require "nursing" care in today's society'* (Resp. 227). An emphasis on the social model of care left many outside the profession doubting the contribution of the nurse to the care of people with learning disabilities. Respondents felt that their qualifications and skills were less valued than those of other nurses. They could not practise in general or mental health nursing without additional training and qualifications, but many posts in learning disabilities were open to nurses from other branches of nursing. Respondents often described themselves as the *'poor relation'* (Resp. 384) or the *'Cinderella'* (Resp. 39) of the nursing profession, claiming that they did not receive the recognition or credibility that they deserve. Many said they consider their profession is undervalued and that they:

> *'... are no longer valued as nurses and our role is not important within the NHS. We are also not encouraged to promote our field of work.'* (Resp. 446)

2.6 Summary and comment

The last 100 and, perhaps more importantly, the past 30 years have witnessed significant changes in the provision of services for people with learning disabilities. Services have usually developed in response to policies, which, in turn were influenced by the prevailing attitudes and prejudices of the time.

At the end of the 19th and beginning of the 20th century the initial optimism regarding the educability of people with learning disabilities was replaced by fear – largely as a result of eugenic ideas. Policies reflected these attitudes by initially promoting and then rejecting the possibility of educating people with learning disabilities. Institutions formed the basis of services and although small specialist institutions were used initially for the purpose of education they were replaced by large institutions designed for the control and containment of those perceived as being a threat to society. The specialist nurse role developed within the growing institutions and soon separately recognised training was established, distinguished from that of mental nurses.

In the 1950s there was again optimism regarding the educability of people with learning disabilities. In line with this new optimism, which emphasised how people with learning disabilities fared better outside the institutional environment, policy began to move towards care in the community. This transitional phase represented a threat to learning disability nurses who were closely associated with the institutions. Other members of the multidisciplinary team became involved in the care of people with learning disabilities and nurses faced the choice of adjusting or being left behind.

The policies of recent years have been largely influenced by the concepts of social inclusion and normalisation, which advocate normal or ordinary living and community integration. Policies have tended to reflect a view that people with learning disabilities have the right to live within the community. As such, community care forms the basis of today's service provision with the provision of care packages for people with learning disabilities now being the responsibility of a number of agencies.

As attitudes toward, and services for, people with learning disabilities have changed, so too has learning disability nursing. Not only has the location of their activities shifted, but the pattern of activities has developed from the provision of care in institutional settings to providing care and therapies and managing services.

CHAPTER 3

THE CURRENT ROLES OF LEARNING DISABILITY NURSES: EVIDENCE FROM PRACTICE

3.1 Introduction

In this chapter we examine the current roles of learning disability nurses. In the first section we develop a conceptual framework using the current literature on nurses' roles and associated competence. We then consider the how nurses define their roles using evidence from our questionnaire survey. Finally we consider the nature of current practice using observational and interview data from our fieldwork.

3.2 Defining nurses' roles and associated competencies

Professionals play a key role in the delivery of health and welfare services in contemporary society, and their knowledge and skills underpin the welfare state. Professionals have been granted privileges by the state, in particular licences to specific types of practice. These licences have been granted in recognition that individual professionals have the appropriate skills and abilities to undertake certain roles. To maintain this licence to practise, the profession must be able to demonstrate that its members have the appropriate skills and abilities to perform these roles. The main mechanism for achieving this is professional education. Initial or basic education assures governments and citizens that each professional has the appropriate qualification and is competent or 'fit to practise'; advanced education assures them that some professionals have developed skills appropriate for more specialist practice and/or are appropriately updating their basic competence.

Central to professional education is the development of the competent practitioner who is 'properly qualified for a task'; and the Board insists that competence is central to the assessment of nursing students (ENB, 1996). However, as Milligan (1998) noted, a precise definition of the competent practitioner is elusive. Competence is usually defined in terms of the task to be undertaken and the competent practitioner has skills that are appropriate and sufficient for the tasks that fall within his or her scope of practice. Thus, Duffield (1991: 59) argued, competence *'requires a fit between a role, the scope of practice and the individual's skills for the job'*.

The nature of competence depends on the nature of the task or role. For example, for a 'craft' such as making pottery or driving a car, the competent practitioner must have appropriate practical skills. The assessment of this type of competence is based mainly on the assessment of practical skills. The competent professional practitioner is expected not only to have appropriate skills but also the theoretical knowledge which enables him or her to understand whether the application of a particular skill is appropriate and what the likely effects of its application will be. As Lankshear et al. (1996) pointed out, although there is no agreed definition of the concept of competency, most definitions include reference to appropriate knowledge and skills for a particular task or job. This can be seen in the 'statements' of competence which underpin vocational qualifications. These are designed to be relevant to work and facilitate entry into, or progression in, employment and should include specification of:

- skills to specified standards
- relevant knowledge and understanding
- the ability to use and apply knowledge and understanding to the performance of relevant tasks (Fletcher, 1991).

However, the competence of modern professionals includes not only appropriate skills and supporting knowledge but also appropriate values. Parsons (1951: 434), in his study of the medical profession, drew attention to *'the complexity and subtlety of the knowledge and skill and the consequent length and intensity of training'* required to produce the competent doctor. However he considered that since professionals allocated valuable resources in modern society they also needed to be socialised into an appropriate value system:

> *'In common with the predominant patterns of occupational roles generally in our society it [the role of medical practitioner] is therefore in addition to its incorporation of achievement values, universalistic, functionally specific, and affectively neutral ... Affective neutrality is ... involved in the physician's role as an applied scientist. The physician is expected to treat an objective problem in objective, scientifically justifiable terms. For example whether he likes or dislikes the particular patient as a person is supposed to be irrelevant, as indeed it is to most purely objective problems of how to handle a particular disease.'* (Parsons, 1951: 434-435)

Within nursing, values tend to be discussed in terms of appropriate 'attitudes'. For example, Duffield noted that the term skill is often used interchangeably with competencies, but she argued that competencies should signify *'not only the performance of a task, but also the underlying knowledge and attitudes to practise or perform the task'* (Duffield, 1991: 56).

There appears to be some unease about explicit discussions of appropriate values or attitudes. For example, Lankshear et al., in their review of the literature on competencies in nursing, concentrated on skills rather than values, though they cited the National Board for Scotland's view that:

> *'Fitness to practise goes beyond adequacy of knowledge and skill acquisition ... Fitness to practise incorporates the murky area of "suitability".'* (cited in Lankshear et al., 1996: 11)

They linked this phrase to assessment, not to values or attitudes. Similarly, they cited examples from the mental health nursing literature that clearly related to appropriate values but interpreted them in terms of the indeterminacy of the mental health nursing role rather than the significance of appropriate attitudes or values.

Taylor suggested that the psychiatric nurse's therapeutic role cannot be described in terms of tasks or procedures, but in terms of attitudes, feelings, understanding and relationships (cited by Martin, 1987). Carpenter and Turnbull supported such a view stating:

> *'Although it is clear that the mental health nurse is to some extent concerned with practical physical aspects of care, we could argue that this part of her work is not the most significant. In addition to doing certain things, all nurses are also required to be certain things, for example, understanding, patient, supportive, comforting and so on. In caring for clients with mental health problems, these "being things are often more important than the "doing things".'* (Carpenter and Turnbull, 1991: 12)

If such views are to be accepted, the task of mapping the competencies required by mental health nurses in community and institutional settings is made difficult, as the identification of indeterminate nursing qualities in either location is inherently problematic (Lankshear et al., 1996: 17).

The framework for defining and assessing the competence of nurses, who are registered by the UKCC, is established by law and is generally referred to as Rule 18A:

> *'(2) The Common Foundation Programme and the Branch Programme shall be designed to prepare the student to assume the responsibilities and accountability that registration confers and to prepare the*

nursing student to apply knowledge and skills to meet the nursing needs of individuals and of groups in health and in sickness in the area of practice of the Branch Programme and shall include enabling the student to achieve the following outcomes:

(a) the identification of the social and health implications of pregnancy and child bearing, physical and mental handicap, disease, disability or ageing for the individual, her or his friends, family and community

(b) the recognition of common factors which contribute to, and those which adversely affect, physical, mental and social well-being of patients and clients and take appropriate action

(c) the use of relevant literature and research to inform the practice of nursing

(d) the appreciation of the influence of social, political and cultural factors in relation to health care

(e) an understanding of the requirements of legislation relevant to the practice of nursing

(f) the use of appropriate communication skills to enable the development of helpful caring relationships with patients and clients and their families and friends, and to initiate and conduct therapeutic relationships with patients and clients

(g) the identification of health related learning needs of patients and clients, families and friends to participate in health promotion

(h) an understanding of the ethics of health care and of the nursing profession and the responsibilities which these impose on the nurse's professional practice

(i) the identification of the needs of the patients and clients to enable them to progress from varying degrees of dependence to maximum independence, or to a peaceful death

(j) the identification of physical, psychological, social and spiritual needs of the patient or clients; an awareness of values and concepts of individual care, the ability to devise a plan or care, contribute to its implementation and evaluation and the demonstration of the application of the principles of a problem solving approach to the practice of nursing

(k) the ability to function effectively in a team and participate in a multi-professional approach to the care of patients and clients

(l) the use of the appropriate channel of referral for matters not within her sphere of competence

(m) the assignment of appropriate duties to others and the supervision, teaching and monitoring of assigned duties.'

(The Nurses, Midwives and Health Visitors (Registered Fever Nurses Amendment Rules and Training Amendment Rules) Approval Order (1989) No 1456)

Clearly the explicit inclusion of 'mental handicap' in paragraph (a) places makes this subject central to all branches of nurses.

While there is no overarching specification for post-registration education equivalent to Rule 18A, the Board provides outline curricula for its Higher and Specialist Practitioner Awards. These tend to refer to the extension of the nurse's competence, but in some cases are

vague about the precise ways in which these are to be extended. Although Rule 18A and the outline curricula provide the general framework for competence, there is no consensus on the best way to operationalise the concept. Two approaches have developed, the empirical and the ideological.

The dominant empirical approach concentrates on identifying the specific skills that contribute to the development of competence. These are identified either by observing practitioners (see Benner, 1984), or an alternative approach is to develop a consensus view within areas of practice (see Lankshear et al., 1996). These types of studies have two effects. They tend to fragment the overall integrated concept of competence into specific competencies. *'Competence ... is given a generic or holistic meaning and refers to a person's overall capacity, and the term ... refers to specific capabilities'* (Eraut et al., 1995: 179). At the same time they focus on specific technical skills rather than underlying knowledge and values. Thus Lankshear et al. (1996) identified 106 separate elements in their 'map' of competence for mental health nursing.

The alternative approach emphasises the underlying ideology. It involves identifying the main objectives which practice is designed to achieve, then examining the ways in which practitioners can contribute to their achievement. We refer to it as ideological, as it often starts from a strong ideological position that is used to define the purpose of practice. This can be seen in a study of the educational preparation of nursing for working with older people. Using ageism (the stereotyping of older people as incompetent and dependent) as a starting point this study was designed: *'to determine the extent to which pre- and post-registration educational programmes ... prepare practitioners to promote patient/client autonomy in the provision of the care to older people, including frail older people'* (Brooker et al., 1997: 9).

This 'gold standard' is then used to assess the competence of actual practitioners and in particular the extent to which they fall short of ideal standards.

3.3 Learning disability nurses and their changing roles

In the remainder of this chapter we examine the current roles and required competencies of learning disability nurses using evidence from our questionnaire survey. We examine the types of activities which nurses state they perform and the associated competencies.

Our respondents were either registered (second level) (77%) or enrolled (first level) (23%) learning disability nurses. Most had worked in the residential/hospital sector (91%) and had hospital titles such as staff nurse (60%), enrolled nurse or sister grades (3.5%). Over two-thirds have remained in the learning disability area. While social services and the independent sector are now the major providers of residential and community care support, most respondents were not employed by SSDs, nor did they work in the private sector. The majority (64.4%) were still employed by the NHS (Table 3.1).

NHS	64.4 %
Private organisation or self employed	16.0 %
Local authority, social services	10.5 %
Voluntary sector	6.5 %
Local authority, education	1.8 %
Joint local authority/NHS	0.8 %

Table 3.1: Current employers *(n = 506)*

However it was clear from respondents' job titles that only a minority retained traditional 'hospital' titles (35.6%), and a substantial minority (43.9%) now had social care titles such a home or team leader. Indeed a substantial minority (22.7%) were not employed as a nurse and nearly a quarter (23.4%) of these respondents did not see themselves as nurses (Table 3.2).

Traditional hospital titles	
Staff nurse	20.4 %
Charge nurse/sister/ward manager	6.8 %
Enrolled nurse	5.4 %
Deputy charge nurse/sister/manager	1.8 %
Agency/bank nurse	1.2 %
Social care posts	
Home leader/manager	11.7 %
Team leader/senior support worker	10.3 %
Senior manager/director – day services/residential services	7.6 %
Deputy home leader/manager	6.8 %
Care assistant/care officer/support worker/residential social worker	4.1 %
Self-employed (own care home)	1.8 %
Other, social worker/inspection officer/carer/project worker	1.6 %
Other nursing posts	
Community nurse/sister	14.2 %
Specialist nurse	3.1 %
Lecturer/tutor	2.5 %
Lecturer/practitioner	0.6 %
School nurse	0.2 %

Table 3.2: Titles of current posts *(n = 514)*

Furthermore only a minority (18.6%) worked within hospitals or specialist units. Half worked either in community-based residential units (51.1%) or provided support to people with learning disabilities living in the community (28.2%; Table 3.3).

Residential and day care	
Residential unit	29.9 %
Group home	9.6 %
Respite care unit	5.4 %
Day care	3.6 %
Nursing home	2.6 %
Community and primary care	
Community nursing/client's home	18.8 %
Various according to client	5.4 %
Office, social services, home	2.2 %
School/nursery	1.0 %
Primary health care team	0.8 %
Hospital-based	
Hospital	7.4 %
Secure unit	6.2 %
Specialist unit	2.8 %
Rehabilitation unit	2.2 %
Education	
College/university	1.8 %
Education department	0.4 %

Table 3.3: Respondents' classification of their working environment *(n = 514)*

The nature of respondents' jobs was reflected in the ways in which they used their time. We asked them to estimate how many hours they spent on a number of activities for the five previous working days. There were a number of activities that respondents claimed they did not spend time on, including domestic activities, child protection and activities related to personal development, personal studies, auditing and research. It was surprising, given the number who were engaged in community and primary care, that travelling did not feature prominently. Three types of activity were prominent: administration, especially record-keeping and attending meetings; providing direct support for users and carers; liaison and education (Table 3.4).

Type of activity	Percentage who spent at least one hour on activity
Administration and management	
Record-keeping, report-writing	93.5 %
Attending meetings	81.1 %
Managing staff and dealing with personnel issues	77.0 %
User and carer support	
Working individually with users	85.4 %
Assessment of users	78.9 %
Health surveillance	62.1 %
Working with informal carers (families/friends)	60.9 %
Working with groups	52.0 %
Liaison activities	
Liaising with the multidisciplinary team	79.2 %
Liaising with outside agencies	69.8 %
Education	
Developing personal competencies	47.2 %
Education staff	46.4 %
Teaching students	25.2 %

NB: Since we invited respondents to estimate activities in terms of hours we present the percentage who spent at least one hour on each specified activity

Table 3.4: Respondents' main activities over the previous five working days *(n = 418)*

We also asked respondents to identify the main competencies, including necessary knowledge, skills and attitudes, needed for their current work. They tended to see competency in terms of required skills, though they also identified the required knowledge-base and appropriate values.

The skills respondents identified were those one might anticipate, given the classification of their main work activities. They saw 'required' skills primarily in terms of managerial and client care skills. Although some identified a need for liaison and educational skills, these were clearly secondary (Table 3.5). They emphasised the importance of managerial skills in terms of the range they felt were necessary for this aspect of their work. Thus while nearly half (46.9%) felt that communication was essential for direct care, they only identified four components: listening skills; relationship-building; interpersonal skills; and counselling. Just over half (56.6%) felt that general management skills were essential, and identified 12 components that were relevant to their practice: financial management/budgeting; resource management; organisational skills; ability to cost services; contracting; strategic development; quality assurance; auditing; marketing; negotiating; networking; and problem-solving.

Type of skill	Percentage of respondents who felt skill was required
Administration and management	
General management	56.6 %
Staff management	38.8 %
Management support such as report-writing	13.7 %
Domestic skills	1.5 %
Health and safety	0.4 %
User and carer support	
Communication skills	46.9 %
Care skills	34.9 %
Clinical nursing skills	17.6 %
User support skills	9.8 %
Therapeutic skills	6.9 %
Liaison activities	
Team working	28.4 %
Education	
Education/training	23.6 %

Table 3.5: Respondents' perceptions of the main skills required in their work *(n = 461)*

Respondents tended to conceptualise knowledge needed for their work in terms of that required to provide care and support for people with learning disabilities. Whereas managing care and services, liaising with other agencies and providing education were all identified as important components, the respondents did not identify underpinning knowledge to this skill (Table 3.6). For example, we could find no underpinning knowledge for education and only legislation as underpinning administration and management of care and services. As noted in our study of risk management and decision-making in community nursing practice, nurses seem to treat these types of skills as essentially practical ones that are learned on the job. They do not appear to be aware of the knowledge which could and should underpin these aspects of practice (Alaszewski et al., 2000).

Type of knowledge	Percentage of respondents who felt type of knowledge was required
Administrative and managerial	
Legislation	19.5 %
User and carer knowledge	
Specialist care	31.2 %
Learning disability	25.2 %
Medication	7.6 %
Current nursing issues	4.1 %
Values	4.1 %
Gained from registration education	3.7 %
Health promotion	3.3 %
Learning disability and the family	1.7 %
Life experience	0.9 %
Liaison activities	
Services	7.6 %

Table 3.6: Respondents' perceptions of the main types of knowledge required in their work *(n = 461)*

Respondents tended to address the attitudes and personal characteristics required for their work in traditional vocational terms. Thus they emphasised traditional values such as 'caring' and commitment (Table 3.7); again this was a surprising finding. Within the field of learning disability there has been a development of a clear and powerful value base for the provision of care and support, especially through the principles of normalisation or social role valorisation. Not only has this been promoted by pressure groups such as Values into Action, but it has underpinned models of care incorporated within current policy and practice (Alaszewski and Ong, 1990; Malin et al., 1999). It is not clear why our respondents made no explicit reference to these types of values. It is possible that they were so deeply internalised and taken for granted that they did not feel it was necessary to refer to them.

Type of attitude/personal skill	Percentage of respondents who felt attitude/personal skill was required
Caring	11.5 %
Committed	8.2 %
Flexible	7.2 %
Confident	5.4 %
Sense of humour	5.0 %
Approachable	4.8 %
Open minded	2.2 %
Professional	2.2 %
Ability to work alone and within a team	2.2 %
Valuing others	1.7 %
Ability to recognise own limitations	1.1 %
Research/evidence based practice	1.1 %
Equal opportunities	0.7 %
Stamina	0.2 %

Table 3.7: Respondents' perceptions of the main attitudes/personal skills required in their work *(n = 461)*

3.4 Perceptions of the role of learning disability nurses

While the questionnaire sample enabled us to build up a profile of the roles and activities of learning disability nurses, it did not provide detailed information on the role of nurses in different settings. Therefore we supplemented these data with 10 case studies that enabled us to both interview and observe the practice of 24 learning disability nurses. In this section we draw on the findings of these case studies to explore these nurses' perceptions of their career choices, their current role and their routine work activities.

3.4.1 Careers and choices

The 24 nurses in this part of the study had been in their current posts for at least one year and several for up to 15 years. A minority indicated that they had had little influence or choice over their place and type of work. Some had applied for and accepted a job for non-work reasons, for example, to be nearer their families, while others had applied for their current job because they needed employment. One said that she applied for her particular post *'because when you first qualify you want to get any job that you can'* (9/1). In some cases nurses had accepted posts as part of the process associated with hospital closure. For example, one service manager said that she had applied for her current post *'because I had to, basically ... I really had little option but to apply'* (7/1), whilst another senior nurse commented *'I didn't apply, I was given it'* (3/2).

However the majority had chosen a specific job because it fitted their career development. Indeed one nurse commented on the importance of changing jobs to build up knowledge and show ambition:

> *'I think it's dangerous, when you're first qualified to be in the same place for many, many years and not have any ambitions ... It's good to move and learn new experiences.'* (4/4)

Criteria for choosing jobs changed during an individual's career. Newly-qualified nurses wanted jobs that would provide opportunity to develop, use skills and progress. Thus a newly-qualified nurse wanted to start her career within the NHS:

> *'... rather than being employed by the private sector [because] ... I thought my prospects and professional development would be better in the NHS rather than in the private sector to begin with.'* (4/4)

Another chose a more 'progressive' area of nursing *'I was particularly interested because it is community rather than hospital'* (5/4).

Perhaps not surprisingly in mid-career nurses were more concerned about seniority and promotion. A minority remained committed to expanding their experience. For example, one experienced nurse wanted to be *'out of the NHS as well, [to] see how [a] private company, charitable company worked'* (5/2). For most mid-career nurses the choice was clear, they could continue working 'hands on' with people or become a manager where they would have little or no user contact. One nurse spoke of seeing herself staying:

> *'... working as a clinician, actually working with clients and developing in that specific area, rather than going into management.'* (2/3)

Another felt 'lucky' that as an H grade nurse she was still able to *'continue hands on work with clients'* (6/1). She added that she would stay *'as an H grade for the rest of my days'* if it meant that she could continue working with people. Several admitted that they were *'not very ambitious'* (5/1, 3/3) and were happy to stay in their current posts. 'Getting on' tended to be associated with moving into management posts and losing contact with people with learning disabilities:

> *'When you start to climb the ladder and become more involved with management issues, the client involvement lessens and, to some extent, for some people, is almost non-existent.'* (3/3)

Those in managerial positions also acknowledged the importance of their post for their career development. One commented *'I felt that [taking on a management post] would be a very good opportunity to expand my experience'* (4/1). Another added that her decision to apply for a post was influenced by her perception that *'it was an opportunity to get some first line management experience'* (1/1).

Nurses in the later stages of their career indicated that their opportunities for development and career progression were more limited. One nurse who was working as a community nurse said:

> *'Unfortunately I can see myself staying here until I retire. I'm not happy about that. It's more to do with my personal situation and the lack of opportunities in the immediate area to move on. I'd like to [move] but it's unrealistic.'* (2/2)

One senior manager who felt that her career development opportunities were restricted was looking to move into education as a possible career path:

> *'The career structure after my role is fairly poor ... the opportunities for me to develop just don't exist ... [I may become] more involved in university work – lecturing, consultancy, that kind of thing.'* (7/1)

3.4.2 The holistic role

While career progression was seen as a choice between low-ambition client care and high-flying managerial roles, when we asked participants about their perceptions of the distinctive attributes of learning disability nursing, they saw it almost exclusively in traditional 'caring' vocational terms. Nurses emphasised the unique knowledge and skills possessed by learning disability nurses in providing care and support for people with learning disabilities. Very little reference was made to the contribution learning disability nurses could make to the management of services.

While other professionals acknowledged nurses' contribution to management of services, nurses themselves seemed reluctant to discuss this aspect of their role and only commented on it briefly. For example, a social worker, noted that:

> *'My perception of their role is that they take a primary role in the day-to-day care planning and nursing ... They're the people who have the day-to-day contact who are responsible for the day-to-day management and care plans for individuals on the unit.'* (4/6)

In contrast, a nursing home manager did admit that *'I suppose I'm the person in control of the home'* (1/1). While another senior manager accepted that her role within the multidisciplinary team was *'a supervisory role'* (7/1).

Nurses were far more comfortable discussing their role in terms of the unique knowledge and skills that were grounded in the special education and training they had received relating to people with learning disabilities. A number pointed out that learning disability nursing *'is the only qualification that deals specifically with all areas of learning disability'* (4/1). Nurses saw themselves as *'the only members of the team that have any specific training'* (2/3). They felt that this made them the specialists within the field and provided the basis for the distinctive role. They saw themselves as the only professionals who worked with individuals with learning disabilities *'from morning to night'* (5/1) providing *'hands-on care'* (6/1). This extended contact with individual users enabled learning disability nurses to build up a knowledge of these individuals that *'is much more in depth than anybody else's'* (4/1).

Furthermore learning disability nurses considered that the knowledge and expertise they had developed about people with learning disabilities enabled them to advise other professionals. For example, one participant emphasised the importance of the nurse as source of knowledge relating to specific individuals:

> *'Your average GP finds it very difficult to establish what's wrong – unless it's very obvious – if there's a lack of communication, so it's down to our observations to be able to give the doctors pointers to what might be wrong.'* (1/1)

Another highlighted the role of the learning disability nurse as a more generalised source of knowledge for other agencies and professionals:

> *'There's so much involved in the daily care and the process and planning of the care all the way through, right from assessing a person to planning, implementing and evaluating and we've got such a huge floor within that, and often people, other professionals, other agencies, come to us for advice.'* (4/4)

Learning disability nurses accepted that other professionals had specialist knowledge about aspects of learning disability, but emphasised their overall and integrated knowledge. They felt they built up comprehensive knowledge and skills because they were 'holistic' practitioners who focused on the entire person rather than on one aspect of their being. They were therefore in the best position to provide leadership to other professions and co-ordinate the overall care and support for individual users. One described the role of nurses in the following way:

> *'I think they're able to draw in other professions after identifying somebody's need and act as a very good organiser, negotiator, facilitator, enabler ... I think they very much broker care for other professions or for the client. And I think that role is quite unique to the nurse.'* (7/1)

Thus nurses saw overall or holistic care as central to their role. In respect of users, one spoke of looking at *'everything in their life'* (4/2); whilst another added, *'You've got to take their whole life into consideration really'* (4/4). Another argued that nurses were looking at everything

'what goes to make a person – the social, the physical, the emotional ...' (2/4). Nurses saw this perspective as a major justification of their position since it provided *'a method of working through and considering all areas and then drawing that back together'* (2/4). This enabled them to provide care suited to the individual. Some considered that providing individualised care was *'second nature'* to them (7/1) since they aimed to *'offer a complete care that suits an individual client's needs'* (4/1).

Nurses felt that such holistic care was underpinned by a special relationship, which they developed with service users. For example, one observed that *'You don't just give out tablets, you don't just dress somebody's leg, it's more a personal relationship, really, with the client'* (4/4) and another that:

> *'You get involved with your clients and ... [it's] not like in general nursing where you might see someone for a couple of days and never see them again.'* (9/1)

According to the nurses interviewed for this part of the research, such relationships were not restricted to individuals with learning disabilities, but included their families. One described learning disability nurses by saying *'you're a family nurse'* (4/2) and another considered that *'you're very much involved with the family and the whole social network of the person'* (4/4).

Nurses felt that this extended holistic role distinguished learning disability nurses from other professions. One said:

> *'I think [learning disability nurses] have a multiplicity of roles that go between professional carer to advocate, sometimes a surrogate parent, and often with that it differs from other forms of caring in that we have to harmonise our jobs together, and treat clients holistically.'* (4/3)

3.4.3 Overlapping activities

The emphasis that learning disability nurses placed on the vocational aspect of their role appeared to be partially a defensive mechanism. When we discussed specific aspects of their role, some were unable to provide a clear specification. One nurse who worked in a nursing home stated that learning disability nurses had *'an undefined role, to be honest'* (5/4). She felt her own role was *'a little bit vague'* and concluded by saying that learning disability nurses:

> *'... tend to have a hand in everything that's going on, but we have one or two responsibilities that are cut and dried – the rest is a bit of a grey area.'* (5/4)

However most nurses were able to identify activities they felt to be unique to their profession and therefore could not be carried out by anyone else. They referred to skills such as assessment and writing reports, management of behavioural difficulties, and building up of therapeutic relationships. One nurse suggested that:

> *'Because of the MDT meetings we are aware of each others' skills and we just call on each other as professionals, as and when needed ... [We] look to each other for what skills we've got. So if I want something like an adaptation I know to go to the OTs and if they want something that's nursie they come here. So it just works like clockwork, really.'* (3/1)

Her example of 'nursie' skills was the traditional nursing skill of recording blood pressure. Another nurse suggested that she contributed to MDT meetings by *'bringing my specialism to that meeting'* (6/1) but it was not entirely clear what she saw as her particular specialism.

Many nurses felt that it was not what they did but how they did it that differentiated them from others. One made this point when he argued that his initial nurse education *'was more to do with attitudes and approach and values, rather than specific clinical factors'* (4/1).

Indeed most accepted there was considerable overlap between their activities and those of other professionals and also the activities of unqualified health care assistants or social care staff.

One nurse working in a multidisciplinary community team noted that her team had earlier agreed that all members – nurses, social workers, and occupational therapists – were interchangeable especially in terms of assessing client needs. *'We're all the same, we can all do the same jobs, we can all assess'* (2/2). However she argued that this approach had not worked, as other team members did not have nurses' holistic approach, *'people weren't assessing the same, people weren't looking at the same things, people weren't looking at it holistically'* (2/2).

Participants were all able to identify specific parts of their work that could be undertaken by other members of the multidisciplinary team. Such areas included *'basic care'* (1/1) and *'day-to-day living skills'* (4/1). One nurse, referring to unqualified support staff, said, *'They could do most things but I suppose the only thing they couldn't do are the drugs-related things'* (5/4). This nurse's colleague – when asked if anyone else could take on her role – replied:

> *'Yes with supervision, I think they could do it … I think it wouldn't be anybody, I'd be very careful, they would be supervised by a learning disability nurse at all times.'* (5/3)

Another went one step further and, in discussing her unqualified colleagues, said:

> *'I would say that we're all equal … The majority of the staff here have been here at least five years and so I would say that their skills were equal to mine.'* (1/2)

Another noted that others could perform her activities but that this did not mean that they were willing to do so especially, the less attractive aspects of her work:

> *'I mean the doctors can do my job. But I would like to see the doctors get in the bathroom and change a dirty [incontinence pad].'* (9/1)

Other members of the multidisciplinary team were also asked whether the nurse's role was interchangeable with that of other members of the team. In some teams other professionals felt there was a considerable overlap and interchangeabilty. Some referred, as one care manager did, to an overlap between certain roles, *'I think … there is a bit of blurring and shared roles and goals'* (2/5). One doctor suggested, *'on some fronts the roles are interchangeable, on others they are not. Their specific skills do overlap and their core skills do not'* (4/5). The view of an occupational therapist working in the community seemed to be the general opinion of the multidisciplinary team members. She pointed out that:

> *'The role of the learning disability nurse can be interchangeable depending on which team they're working on and the expertise within that team.'* (2/7)

Some members of the multidisciplinary teams identified specific areas of practice in which roles were interchangeable. Such areas included mental health, behavioural work, and work relating to personal relationships and sex education. However most professionals accepted that nurses' day-to-day contact with users made them an important source of information. For example, a social worker noted that:

> *'Nurses are doing the day-to-day assessments, evaluation, treatment, whereas the social worker is just involved in using the information that comes from nurses to look where care planning and discharge is coming up.'* (4/6)

Similarly a GP working in a forensic unit described how learning disability nurses:

> *'Report on the activities during the week, how they perceive the clients' needs and how they perceive they're improving, or occasionally if they're slipping back into mental health problems.'* (4/5)

Other members of the multidisciplinary team emphasised the role of nurses in managing and co-ordinating care. A care manager pointed out that they put:

> *'... together packages of support or development for that person [with learning disabilities]. They're very good at identifying specific pieces of work and working with that to put together packages of support.'* (2/5)

Others highlighted the role of the learning disability nurse in service development. One care manager reported that nurses, *'carry out a developmental role in services, identifying weaknesses in the services overall and flagging that up'* (2/5). Other professionals acknowledged nurses' knowledge and ability to manage specific user needs. For example, a social worker valued:

> *'... guidance in terms of behavioural and more challenging behaviour difficulties. Both guidance to ourselves and other groups of staff, or carers, people with learning disabilities.'* (2/8)

An occupational therapist working in the same team added that, *'anything to do with anger management, with challenging behaviour, advice on behaviour modification tends to go to the nursing team'* (2/7). Other members of the team also emphasised the nurse's role as having a responsibility for, as a therapies manager pointed out, *'the assessment of health needs of clients'* (2/6).

Multidisciplinary team members who worked alongside community nurses were clear about what they perceived to be the role of nurses within the team. In addition to the above, they reported their experience that, as an occupational therapist commented:

> *'The nurses in this team are looking at any health issues; advice on GP visits, overlooking medication, monitoring side effects of medication, going along to GP and consultant visits, anything to do with health implications.'* (2/7)

3.4.4 Pressure from below

Nurses identified their distinctive role in terms of holistic care, while at the same time acknowledging that their activities overlap, not only with those of other professionals but also those of unqualified staff. Other professionals also recognised an overlap, but saw nurses as having distinctive expertise in terms of the needs of users and in managing services. However, unqualified workers such as health care assistants and support workers were unwilling or unable to recognise the distinctive nursing role. One support worker in a day centre suggested *'they all sort of muck in'* (3/5). Another added that *'they do work as part of a team'* (5/5). Many care assistants struggled to identify specific roles and instead reported that nurses did *'exactly the same as the rest of us'* (1/4). Another support worker, who worked as a deputy manager of a residential home, added that, learning disability nurses did *'nothing that's different to any other member of staff'* (1/5) because, *'they don't have a role* per se *as nurses, because we're registered for social care not nursing care'* (1/5). His colleague, an experienced care assistant, added that *'their role is just the same as ours. There's nothing really different that they do that we do'* (1/3).

Most unqualified workers thought that they could perform most of the activities of nurses. The experienced support worker above believed that the nurse's role was *'totally interchangeable'* with his own (1/5). He went on to demonstrate how certain skills – particularly in relation to management – were not related to nurse education:

> *'I'm not sure it's actually taught all that much actually in the nursing courses, it's just – you just do it ... you get your [nursing] qualifications and can go from being a student almost directly to a management role with virtually no previous experience.'* (1/5)

He concluded that, *'I don't see that they actually perform a different function in here*

from anybody else' (1/5). Amongst those who did not particularly value the contribution of the learning disability nurse was one health care assistant who said:

> *'In my old job [a long-stay institution] they were very important. But community care? I don't know ... I don't know if, I don't think it's [a learning disability nursing qualification] a necessity.'* (5/5)

Several unqualified staff questioned the value of a nursing qualification. One care assistant in a residential home appreciated the personal skills of the nurses she worked with, not their formal qualifications. She said she valued them:

> *'... but not because of their role, not because of the qualifications they have, just because of the type of people they are. If they weren't nurses then they'd be doing exactly the same ... They have lots of skills but I think they'd have those skills whether they'd had nurse education or not.'* (1/4)

Another health care assistant within a nursing home felt that given some training:

> *'Anybody could basically do [the nurse's role] without [formal nurse] education, because I have worked at places where they haven't had to have a qualified member of staff there.'* (5/6)

Where unqualified workers acknowledged nurses' unique skills they either saw them in terms of specialised technical skills or general management ability. Some valued the specific care and management skills. For example, an unqualified worker in a forensic unit pointed out that:

> *'Obviously they write all the care programmes and take their observation levels and get a care team together and initiate meetings and care programme planning and things like that.'* (4/8)

Other health care assistants accepted that the nurse's role was slightly different to their own because nurses had to carry out certain duties for which a qualification was required. One assistant in a nursing home reported that, *'they've to do the medication, basically, and the paperwork that we're not allowed to do'* (5/6). In one day care centre, the support workers focused upon nurse's medical knowledge and one pointed out, *'I think it's just the medical side that we can't deal with. I mean we do everything else but obviously the medical side'* (3/5).

A support worker in a forensic setting felt that she and her colleagues would be capable of carrying out some aspects of the learning disability nurses' role and added that:

> *'I would have said the majority of support workers would be competent at giving out the drugs and maybe not taking charge of the whole shift but certainly doing more nursie-type jobs, if you like, rather than just like bathing.'* (4/8)

Another support worker, this time from a residential setting, felt that the only aspect of the nurse's role she would not feel competent to undertake was that related to management. A care assistant in a nursing home pointed out that nurses *'oversee everything that we do'* (5/5) and another noted the importance of the nurse as *'an authority figure'* (3/4).

Nurses' professional contribution was also valued. One unqualified worker spoke of the way in which learning disability nurses *'come in with fresh ideas and new ways of approaching things'* (5/7). A deputy manager of a residential home saw that they might have a valuable contribution to make to the team:

> *'... in terms of possibly providing a base line and a level with professional ethics, yes in sort of – not in the actual way they actually treat or work with clients or work with staff – but possibly having a professional qualification might mean that they are more open to self examination, or examining the service in a more detached way.'* (1/5)

3.5 The role of the learning disability nurse: evidence from practice

Data from the interviews indicated that learning disability nurses emphasised the vocational aspect of their role. They saw their main role as providing direct care for users and their families. In our observational work we identified nurses who were heavily involved in hands-on care, but predominantly these were junior, the majority of nurses' time was spent in administration and management, even when their job title signalled direct user care. We begin our analysis by examining the activities of nurses who were predominantly providing direct client care. We then consider individuals who were also providing advice and guidance to others providing direct care, and finally examine nurses who were predominantly managing services.

3.5.1 The nurse as care-provider

In our observations we were able to identify a number of nurses whose main activities centred on providing direct patient care. Our example comes from a multi-purpose unit located in purpose-built facilities located in the grounds of a general hospital in the North of England. The unit acts as the centre for the learning disability services for a large town and provides day care services as well as short-break respite care for up to 10 individuals and longer-term care for up to 35. Our observation took place in a sub-unit that provided residential care for eight individuals with severe learning disabilities. We observed Rachel, a registered learning disability nurse, on a shift during which she was the most senior nurse and had overall responsibility not just for her sub-unit but for the whole residential unit. During her debriefing interview Rachel indicated that her normal pattern of activity was altered by two factors. She was in charge of her sub-unit and also the most senior nurse in the whole unit. This increased the administrative and management component of her work. However the sub-unit had also been short of staff so she had also had to help with direct user care.

It is clear from the overall profile of Rachel's activity during the shift (Table 3.8) that the direct care aspect of her work took precedence. While she did spend time on administrative work (97 min.; 28%) and even some educational activity (8 min.; 2%), for most of the shift she was engaged in direct care (241 min.; 70%), providing medication, toileting and bathing and helping residents eat. Thus while she did spend time on paperwork (59 min.; 17%) or on the telephone (50 min.; 14%), she spent most of her time in the residents' living areas.

06.50	User	Arrives – settles a resident who is frustrated
07.00	Break	
07.02	Management	Checks schedule to see which staff are on duty, checks communication book, checks night book, checks day book for past two days (because was off)
07.08	User	Handover
07.11	Break	
07.13	User	Stops resident banging on glass and sits down with her
07.17	User	Takes resident to the toilet
07.23	User	Nursing assistant arrives and checks in with Rachel – tells her that the hot water will be off, so they need to get the residents bathed quickly
07.28	Management	Checks 'Bleep Book' for entries (i.e. emergencies from other wards), checks day book again, fills in diary
07.40	Break	
08.35	User	Prepares medications in office – takes out to individuals
08.50	User	Goes into toilet to assist resident
08.52	User	Medications

Table 3.8: Rachel's main observed activities *(continued ...)*

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09.01	Management	Back to office, answers phone
09.02	User	Medications
09.06	Management	Fire siren goes and checks panel to see if it's a scheduled test (it is)
09.07	User	Medications
09.11	Management	Phone rings – enquiry concerning residents' money
09.12	User	Medications
09.28	User	Toiletting and bathing
09.42	User	Breakfasts and drinks
09.50	User	Toiletting and bathing
10.27	Management	Phone calls about broken washing machine
10.32	User	Toiletting and bathing'
10.43	Management	Maintenance staff come to fix pipe – goes back to lounge, and then to office to check on day book
10.50	User	Phone call about resident
10.52	User	Phone calls about resident's parents and their travel expenses
11.05	Management	Checks day book
11.07	User	Helps nursing assistant monitor resident's needs
11.15	User	Phones taxi for resident and parent visit
11.21	Management	Fills in day book
11.22	Management	Gets a line for the maintenance staff who need to use the phone
11.24	Management	Fills out menu sheet
11.26	User	Guides resident from office to lounge
11.32	Management	Form to get resident's money for clothes – orders money on invoice
11.34	Management	Phone call, to collect 'pocket money' [sic] for resident from office
11.36	User	Resident begins to scream – so sings to resident
11.46	Management	Fills out finance order form in the office
11.48	User	Returns resident from office into lounge
11.50	Management	Nursing assistant comes in to get cash to take resident out
11.55	Management	Phone call for staff coverage
11.56	User	Asks nursing assistant to dress resident
11.58	Management	Phone call for staff cover
12.00	User	Phone call to arrange taxi for resident
12.02	Management	Records taxi in diary
12.03	Management	Phone call for staff cover
12.07	Management	Fills out daybook and lets maintenance men out
12.16	Education	Reads a research report
12.24	Management	Fills in daybook
12.26	Management	Phone call for staff cover
12.27	Management	Checks drug cards
12.30	User	Lunch and toiletting
12.58	Management	Paperwork, finance and maintenance request
13.11	User	Medication
13.14	Management	Paperwork, order for new sign
13.18	User	Phone call from resident's family
13.22	Management	Phone call to maintenance about changing a lock
13.24	Management	Phone call for staff cover
13.26	Management	Received keys from nursing assistant
13.28	User	Handover
13.35		End of observation period

Table 3.8: Rachel's main observed activities *(continued)*

Rachel also completed a diary, which covered eight shifts, and we identified her main activities from this diary (Table 3.9). Given the nature of the record we are unable to quantify this source but this type of analysis is likely to underestimate common activities because they are mentioned more than once, and overestimate uncommon ones that only occur once. Even with this caveat it is clear that the user care activities dominated the diary. We identified 61 separate activities. Over half (32; 52%) were related to user care. The remainder were administrative (15; 25%), liaison (8; 13%) or educational (6; 10%). However from the comments Rachel included in her diary, it was clear that not only did direct care predominate but she also saw these as the most valuable activities that gave her the greatest satisfaction. For example, at the end of the first day's entry she noted:

> *'Most rewarding times. Spent time with residents – breakfast – use of behaviour care plans, when able to calm residents with non-aversive approach. Using alternative communication.'*

While at the end of the second day she commented:

> *'Very rewarding day – I can see a solution for difficult behaviour of resident with help of consultant. Appreciated ward manager's support.'*

On the fifth day she made the following comment following one incident:

> *'Resident approached me with his arms outstretched. Indicated he wanted a "love". Same given. Took time to spend with him. He enjoys playing with a ball. A GOLDEN 15 MINS SPENT!!'*

Type of activity
User and carer support
Communication and contact
• updating parents/informing them of events
• giving/receiving handover
• advocate for users
• socialising with users – eating and drinking with them
• entertaining users
• taking users out in her own time
• physical contact (hugs) with users
Care planning and monitoring
• participating in individual programme planning
• preparing for users' individual programme planning meeting
• developing care plans for users with challenging behaviour
• evaluating care plans
• observation of users' – behaviour – health status
• assessment – weight – visual
Direct social care
• supervision of users
• supervising meal times
• managing challenging behaviour
• ensuring users' dignity and privacy are maintained
• protecting other residents

Table 3.9: Analysis of main activities in Rachel's diary *(continued ...)*

Direct physical care

- ensuring users receive appropriate food
- washing and dressing users
- assisting users with toileting
- administering medication
- administering PRN medication for challenging behaviour
- administering PRN pain relief
- administering the 'flu vaccine to eight residents
- giving skin care treatment to a user
- administering first aid to a user's cut
- care of a user during an epileptic seizure
- lifting and moving user

Administration and management

Paperwork

- written evaluations
- incident forms
- sickness/annual leave/ordering
- sorting through the post
- organising the ward diary
- tracing missing paperwork

Meetings

- attending ward meeting
- handing over to staff

Staff management

- Covering shifts
  - staffing issues – trying to obtain extra staff
  - persuading staff to work longer hours
- Personnel
  - supporting staff – trying to encourage 'staff to remain positive'
  - contacted staff health with a query about Hep. B and Tetanus immunisations for staff
  - planning the day for the staff
  - arranging outings – planning which staff will go
  - supporting staff – having lunch together

Liaison activities

Joint work

- OT assistant in the area helping to take users out
- assists doctor to take blood

Communication

- referrals to doctors
- liaise with the physiotherapist
- contact with the psychiatrist
- asked for opinion by the psychiatrist
- communicating with pharmacy
- communicating with the MDT

Education

Self/personal

- received support from the ward manager
- 15 minutes spent with her preceptor for 'peer support'

Others

- help Health Care Assistant with her NVQ work
- supervise student nurses
- preparing for the arrival of the new student nurses
- induction programme for new Health Care Assistant

Table 3.9: Analysis of main activities in Rachel's diary *(continued)*

3.5.2 The nurse as specialist

In a number of the teams we observed the nurse acting as a specialist, providing specific forms of therapy and advice. Sometimes this was provided directly to people with learning disabilities, but more frequently the nurse provided advice and support for others, either parents or staff in residential units. In this section we examine the implications of this type of role on activity patterns by examining the role of one nurse, Karen, who specialised in challenging behaviour.

Karen worked in a multidisciplinary team in the Midlands, which provided support for users in the community. It received referrals from a variety of sources (courts, social services, families themselves, and a central residential unit) which were passed to the team whose base was in the psychology department. The team held care management meetings in which they decided if an individual would be a suitable user, what kind of care/support was needed, and which staff should take the lead role. When Karen received a new case, she carried out an initial interview with the user and his or her carers to establish what the difficult behaviour was and why it was a problem, and whether there were other problem behaviours. Then she carried out a period of direct observation – for 20 hours or so, shadowing the user and any family. She used this information, and background information, to prepare a global assessment. This included an assessment of motivations – establishing what the functions of the target behaviour were. Using this analysis, she developed a programme and helped staff or families (and in some cases users) to develop coping strategies. She explained that often this meant explaining a service user's background to staff to develop their insight and encourage understanding and compassion rather than anger.

Observation of one of Karen's shifts indicated that her work was predominately providing advice and support to users. While she had limited direct contact with users, she was actively involved in identifying the causes of challenging behaviours and developing strategies for dealing with it. This accounted for nearly half of her activities (191 min.; 45%). The rest of her time was divided between travelling (76 min.; 18%), liaison work (76 min.; 18%) and management (77 min.; 18%) (Table 3.10).

09.14	Travel	To first appointment
09.30	User	Investigate incident with user, advise home on management and update on other users and home
10.29	Travel	Drive to next user
10.40	User	Review user who can be violent, check medication and behaviour and prepare for user's move to another unit
11.21	Travel	Drive to the central unit
11.40	Management	Arrive at central unit – check phone, mail and desk
11.50	Break	
12.03	Management	Interviewing applicants for new post
13.10	Liaise	Lunch with other member of team and a university lecturer
13.45	Travel	
14.05	Break	
14.10	Liaise/user	Chair case conference at a day centre to discuss user's future
14.48	Liaise	Following formal meeting talks to individuals informally
14.54	User	Talks to keyworker of user who is self-harming
15.30	Travel	
15.40	Liaise	Exchange of information with staff at a unit
16.15	User	User in disturbed condition, seeks to calm him
16.32		End of observation

Table 3.10: Karen's main observed activities

While analysis of these observation notes indicated that Karen's main activity was providing support for carers and users, it was difficult to identify educational activities. This is perhaps misleading as during her visits she undertook a number of linked activities, primarily focused on challenging behaviour but also involved liaison, educational and administrative work. This can be seen from the more detailed record of Karen's activities during one visit to a service user living in a residential home.

> **Extract from observation:** *Keith is diagnosed as autistic and psychotic (history of physical and sexual abuse in foster homes and through carers), and lives in a private home with paid carers. Keith is an extremely anxious person – and therapy had concentrated on bringing down his anxiety (teaching him management strategies, and controlling the environment so it was predictable and calm). The previous evening Keith had 'kicked off' – smearing faeces on the walls and on himself, smashing his room up, breaking the windows and hurting himself (classic behaviour for autistic individuals). After his outburst, he had calmed down. Workmen were at the site, repairing the damage, whilst Keith was at day care. The staff were understandably upset, and the unit manager needed to be calmed down – to have a technique or strategy to manage Keith. Karen reads the case notes, Keith's history and checks his medication records. She collects the post about other patients, and is brought up to speed about which staff are working there, which other residents are living there, and who's moving on/in etc. She discusses the incident with the unit manager – who indicates that Keith has been getting progressively more anxious for the last two months, after a remarkable period of two years in which he has not committed any violence against people or property. The manager is looking to Karen for reassurance, guidance and support. Karen reassures her that the staff are capable, and should make the decisions about what to do, within general guidelines, which she supplies, and which have been previously agreed. Karen says they should stick to the routine therapy, whilst the manager is nervous, and wants to 'clamp down' on Keith. Karen suggests that they stick with the programme of clear boundaries and rigid routines, and low arousal environments. Karen schedules meeting with Keith later on – to assure the staff that his needs will be assessed.*

An analysis of the activities that Karen recorded in her diary also gave a more balanced picture of her role (Table 3.11). Excluding travelling, we identified 34 separate activities. User care predominated (14, 41%) but the remaining activities were relatively equally divided between management (6, 18%) liaison work (6, 18%) and education (8, 23%).

Type of activity
User and carer support
Assessment
• motivational
• behavioural, identifying triggers and contributing factors
• psychological tests and assessments
Observation
• general
• of users' behaviour
Care planning and monitoring
• implementing care methods
• evaluation of care
• evaluation of treatment or therapies
• evaluation of services available to users
• setting up planning meetings
• chairing planning meetings
User contact
• reading users' notes
• visiting users at home
• responding to emergency calls
Administration and management
Paperwork
• report-writing
• general paperwork
Meetings and communication
• answering phone inquiries
Staff management
• evaluating staff/user cover
• assessing how staff are 'coping' with user's behaviour
• debriefing staff following an emergency incident
Liaison activities
Liaison
• liaising with purchasers of services
• liaising with users' homes
• receiving referrals from consultant psychiatrist
Meetings
• discussion with the social worker
• weekly MDT meetings
• attending/participating in case reviews

Table 3.11: Analysis of main activities in Karen's diary *(continued ...)*

Education

Self/personal

- received supervision – included personal reflection
- attending training

Others

- arranging staff training
- training staff on how to reduce injury to self
- training staff on autism
- training staff to understand the users
- supervision of a community nurse
- supervision of a psychology student

Other

Travel/driving

Table 3.11: Analysis of main activities in Karen's diary *(continued)*

3.5.3 The nurse as manager

In all our case study sites, some registered nurses were undertaking roles that were explicitly labelled as managerial, for example, team leader or unit manager. It was clear that these had limited opportunities for user contact and spent the overwhelming majority of their time administering and managing services.

To illustrate the impact of this we will concentrate on the activities of one acting unit manager (Brian) responsible for a forensic unit in a large city in the North of England. The unit provided assessment and rehabilitation for individuals referred from the courts or who had challenging behaviour. Brian clearly felt that his care role was an important part of his identity, for example he was developing such skills by studying for a diploma on the care of the mentally disordered offender. However as will be clear from our observations and his diary he had little direct contact with users.

We observed Brian's activities for one shift starting at 10.50am and finishing 3.28pm (Table 3.12). It was clear that Brian spent the majority of his time in administration and management (115 min.; 41%) and the least proportion of his time in care activities (40 min.; 14%). The remainder of his time was spent either in liaison (71 min.; 25%) or education (55 min.; 20%). Brian spent the overwhelming part of his day in meetings (121 min.; 45%), on the phone (57 min.; 21%) or doing paperwork (57 min.; 34%).

10.50	Management	Sorting paperwork
11.02	Liaison	Phone call to arrange appointment time with new OT
11.04	User	Talk to staff who are moving the belongings of a resident who is being discharged
11.05	Management	Write reference for ex-staff member who is applying for Probation Service
11.10	Education	Phone ward to arrange training for staff
11.17	Education	Schedule training for staff in keeping with Health of the Nation targets
11.23	Management	Talk to the Assistant Psychologist, about running a sports session with nurses in the mornings. Sort through types of equipment, and decide what they should buy
11.35	Education	Phone call to arrange training
11.41	Education	Training paperwork
11.52	Management	Phone call about the appointment with the new OT
12.02	Education	Phone call to arrange training programmes in mentally disordered offenders
12.07	Management	Phone calls regarding the meeting with the OT
12.15	Education	Paperwork regarding training
12.16	Education	Phone calls about training
12.21	User	Go to reception and talk to LD nurse – discuss patient who is angry and truculent after incident with doctor
12.25	Management	Phone call to OT to arrange appointment
12.26	Management	Clerical work about staff coverage
13.05	Liaison	Meet unit psychologist
13.15	Management	Tidy up elements of an incorrect discharge
13.30	User	Handover in the reception – two support workers, two LDNs
13.58	Liaison	Meeting with clinical co-ordinator for OT and physiotherapy in mental health and learning disability
14.57	Management/ user	Discuss payroll problems and individual resident with two support workers
15.04	Management	Tidying up desk in preparation for the next day
15.09	Education	Phone call about training
15.17	Management/ education	Arranging staffing, scheduling, bank nursing and induction for bank nurses
15.23	Management	Phone call to rearrange a meeting with the OT
15.28		End of observation period

Table 3.12: Brian's main observed activities

Brian also completed a diary and in Table 3.13 we identify the main activities. We identified 52 separate activities, 30 (58%) of these concerned administration and management and 21 (40%) were to do with direct user care. It was clear that Brian felt frustrated with his lack of involvement with residents, for example, towards the end of one shift he noted *'drugs round – my only contact with patients'*. And at the end of the diary entry for that day he wrote *'I've spent approx. 20 mins with patients today and feel I've done nothing worthwhile – time spent on paperwork'*.

Type of activity
Administration and management
Finance
• dealing with budgets
• pricing up equipment
• dealing with invoices
• signing money request forms
Paperwork
• order stock
• open and read and sort mail
• note writing
• complete and sign incident forms
• sign timesheets
• complete sickness returns
• prepare documentation for new admission
Meetings
• prepare the room
• arrange refreshments
• receive management handovers
• attend senior staff meeting
Staff management
• covering shifts – ringing staff to cover staff sickness – rang occupational health about a member of staff's sickness record
• personnel – speak to them about a member of staff's resignation – complete relevant documentation – recruitment of nurse – arrange job advertisement for new staff nurse – send a letter about a new starter's salary – meet new staff nurse for informal chat – write a reference for a member of – staff support – staff 1:1 supervision – answer user queries
• other – prepare list of policies and procedures already in place for the senior nurse manager – ensure Mental Health Act requirements re: leave are met and up to date – request information on risk assessment
User and carer support
Communication
• participate in handovers
• represent patients at meetings
• advocate on the user's behalf
• discuss users with staff
• with angry parent – feedback to other staff
• answer user queries

Table 3.13: Analysis of main activities in Brian's diary *(continued ...)*

User and carer support *(continued)*

Monitoring

- read weekly user summary
- read individual Kardex

Direct contact

- attend call about breach of security
- resolve potential conflict between users
- do drugs round

Liaison activities

Liaison

- liaison with the MDT members
- liaise with GP and doctor
- liaison with outside agencies – e.g. courts and police
- answer police query

Meetings

- weekly MDT meeting
- represent unit – resist inappropriate admission at the MDT meeting

Education

Self/personal

- receive clinical supervision (new role)
- attend education course

Others

- source of advice for staff (own ward and others)
- look at training opportunities for staff
- encourage staff member to teach other staff

Table 3.13: Analysis of main activities in Brian's diary *(continued)*

3.6 Summary and comment

The findings in this chapter indicate the importance of using multiple sources of data to examine nurses' roles of nurses. If we had relied on interviews with nurses, we would have got the impression that the primary role of nurses is as providers of direct user care. However, other sources of data indicated that while some nurses, especially relatively junior nurses in residential settings were predominantly 'carers' and spent the majority of their time providing direct care, this was by no means universal. As they progressed in their careers so their roles changed. They moved into more specialist or managerial roles. This shift was reflected in the changing pattern of activities, and was clearest for senior nurses in managerial roles. It was difficult to identify any direct care in their daily work, which was management and administration dominated. They spent most of their time doing paperwork, answering the phone or in meetings. Specialist nurses had a more varied workload; providing support to users in a variety of settings and travelling between these settings were major features of their working day. While specialist nurses did provide direct services to users more often, their specialist input was often targeted at one remove, to those individuals who provide direct care and support for users, their families or residential staff.

The apparent emphasis on the care role, which was evident in the interviews with nurses, can be explained by a number of factors. Nurses were attracted to the profession because they wanted to care for users and it was clear from the diaries that they valued this aspect of

their work. While many had moved into managerial posts, they saw this as a necessary price of promotion and wished to maintain their identity as nurses who provided care. The emphasis on the caring component of nursing can also be seen as defensive. While the professional members of the multidisciplinary teams clearly recognised and valued both the caring and managerial skills of nurses, unqualified workers did not. It appeared that nurses responded to this pressure from below by emphasising the vocational and caring component of their role.

Our observation of nurses working within multidisciplinary teams indicated that there they undertook a variety of roles requiring different skills and competencies. The most common was providing care within a residential setting either in community or forensic units. In both cases nurses needed the skills and knowledge to plan and deliver care to a variety of users. We were also able to identify more specialist therapeutic roles in which the nurse acted as a specialist adviser or consultant. While there was some contact with users the advice provided was often to paid or informal carers. Nurses performing this role needed specialist knowledge, for example of challenging behaviour, the ability to assess needs in this area and the skill to provide advice and guidance and in some cases to deliver specialist therapies.

4.1 Introduction

In this chapter we explore the relationships between user and carers and learning disability nurses. We commence with a discussion of the changing position of both users and carers in the caring environment. We then explore user and carer views of what the role of learning disability nurses is, and should be. Finally, we discuss the involvement of users and carers in the educational process.

4.2 The changing position of users and carers

Our chapter on the development of learning nursing disability nursing was influenced by official accounts and perspectives. This chapter focuses on users and carers. It starts with a consideration of user views, noting that within the health service, and welfare provision generally, they have emerged from largely passive to more articulate positions.

Accounts of hospital care for people with learning disabilities have swung from the benign to radical critiques of institutions as abusive and coercive. However, until fairly recently there have been few opportunities for users to comment. As nurses have noticed, the critique of hospital care could implicate them in its failings. Corkish and Heyman (1989: 217) conceived of hospitals as *'condemned as incapable of providing a good quality of life for people with learning disabilities'*. The series of inquiries into hospital scandals provided damning evidence of cruelty, ill-treatment, threatening behaviour, theft and lack of care (e.g. Committee of Inquiry into Allegations of Ill-Treatment of Patients and other Irregularities at the Ely Hospital, Cardiff, 1969). But such reports failed to elicit the patients' perspective: *'the disabilities and communication problems of patients were deemed to be so excessive that evidence from them was not sought. The views of Ely's patients are missing'* (Manthorpe, 1999: 112).

Patients' accounts of hospital life tend to appear retrospectively, particularly after closure. Potts and Fido (1991), for example, successfully encouraged former patients to provide an account of hospital life. They quote Grace, who observed:

> *'It used to make me laugh at the Park. They were so deceitful at the Park. Why couldn't they have told the truth when they used to have the Board of Control come round every year. Well, they used to get all bathrooms and put towels on baths. Well, we never had towels. And they used to put soap in sinks. We never even saw soap. They did all that, just to make an impression.'* (Potts and Fido, 1991: 23)

While such accounts focused on the environment, others provided examples of nursing practice from the patients' perspective. Jean Andrews (Andrews and Rolphe, 2000) reported hospital life as 'work' and described how she used to help patients, children and those with profound disabilities, in respect of feeding, washing and dressing. Her account presented a view of nurses who could be friends and colleagues. It also included those who were authoritarian and punitive: one nurse was referred to as insisting on early morning starts:

> *'Sergeant Major, they used to call her, because she used to go up and down, up and down (the dormitory) ... we had to get up early every morning to do some scrubbing on our own ward before breakfast ... I don't know why we had to do it – I think it was just to punish us ...'*
> (Andrews and Rolph, 2000: 36)

These detailed pictures of hospital life allow us to see that nurses and patients were part of a system and not always in opposition. While former hospital residents have often

criticised the policies that confined them, and the neglect and low standards they experienced, they have provided views of staff who were often similarly marginalised. Gloria Ferris, for example, (Cooper et al., 2000) observed:

> *'Some of the staff were quite nice to me on the wards I've been on. They were alright but I didn't like the place itself'* (Cooper et al., 2000: 190)

Since the closure of hospitals, the importance placed on the views of service users has grown. Relationships of partnership have evolved, with new opportunities for user-led services emerging in community care. This change is marked by terminology – patients have become clients and increasingly 'service users'. It is thus more difficult to define tightly the relationship between a learning disability nurse and the 'patient'; the traditional context and established roles have changed for all parties. However some enduring points remain – in particular, the emphasis on relationships and concepts of health as broad and multi-faceted. These points are demonstrated in material from our focus group interviews with users and carers. Such points have direct relevance for the educational process in establishing whether it meets users' and carers' priorities.

4.2.1 User and family involvement in education

In parallel with increased emphasis on developing partnership with users of services and family members or carers, there has been growing attention to the potential for user and carer participation in professional learning. Within the social work profession, CCETSW has sponsored a series of publications outlining models of user engagement in social work education. Crepaz-Keay (1997), for example, discussed the involvement of mental health service users at a number of levels. Manthorpe (2000) developed a framework for carer involvement in social work education across disability groups, and noted a spectrum of:

- personal testimony or witness
- specific problem definition
- engagement in curricula, assessment and planning.

Taylor (1997) observed that such participation is challenging to professional educators, since it requires a renegotiation of a dyad of student and facilitator to a triad of student/facilitator/user. Furthermore, Low and Weinstein (2000) argued that such involvement is particularly relevant to interprofessional education, since user involvement can ensure the focus remains on service delivery rather than professional differences. Little exists however on the perspective of service users and carers in nurse education aside from the arena of mental health, although there is some indication that advocacy groups and parents of children with learning disabilities are likely to be engaged in such initiatives. Fisher and Coyle (1999) conducted a small-scale survey in Wales and found little evidence of user involvement in learning disability nurse education.

One of the few accounts of professional education involving carers, which addresses how families perceive teams, is provided by Turner et al. (2000). Whilst considering carers who had been supporting a person with terminal illness, this educational initiative for medical, nursing, social work and therapy pre-qualification encouraged students to learn of each others' roles and then to hear of the experience of family carers. Students reported that this form of learning was informative and moving. They could see how co-ordinated care was infrequently achieved and often inflexible.

4.2.2 Comment

The development of more positive attitudes towards people with learning disabilities and their families has been associated with an increased concern to access and act on their views. This was initially manifest in studies of life histories based on experiences of institutional care, though as the patterns of support have changed so have the narratives. Associated with this

has been a concern to increase the involvement of users and carers in the planning and delivery of both services and education.

There is now a research literature, albeit of recent origin, which provides evidence of a multiplicity of methodological approaches to involving people with learning disabilities as respondents in research projects (e.g., Atkinson, 1997; Atkinson et al., 1997; Hussain, 1997).

> *'In the matter of their own lives, people with learning disabilities are "expert witnesses" who speak from a secure position of knowledge.'*
> (Booth and Booth, 1994: 23)

With the growing use of focus group methodologies, people with learning disabilities have been included as participants (Northway, 1998). Similar issues arise in respect of their involvement in this form of research as with other methodologies (for example, the debates over reliability, validity, articulateness and response bias found in Booth and Booth, 1994, are not confined to their narrative techniques).

In the remainder of this chapter we consider user and carer perceptions of the roles of learning disability nurses and their involvement in education.

4.3 Perspectives on the role of the learning disability nurse

This section brings together people's comments about the tasks and roles that they associated with learning disability nurses. These were largely related to their personal experiences, but some abstract ideas were also developed. The accounts of people with learning disabilities are provided first.

4.3.1 User perspectives

4.3.1.1 Activities unique to nurses

Users tended to see the distinctive activities in functional or medical terms, such as taking blood pressure or giving medication. John, for example, described the tasks his learning disability nurse undertook:

> *'And when I go to the clinic with [nurse] he always takes my blood pressure and that and asks me ... and asks me to put my hands up like that to see whether there's any shakiness or things like that and he took me to get my injection and that's about it.'* (8/1)

In the same group, David described a similar process with the same learning disability nurse, *'I usually go to his clinic every fortnight isn't it? To be weighed and that and to take my blood pressure'* (8/1). This functional perspective was repeated in the large focus group that usually met as a self-advocacy group in a day centre. One participant reported that her learning disability nurse: *'Keeps an eye on my blood pressure. I've got very high blood pressure and weak ankles so she keeps an eye on me'* (6/1). Another man described the role of his learning disability nurse when he was staying in short-break accommodation:

> *'When I'm staying at [residential unit] he brings my tablets and medicines and gives them at the time prescribed to take.'* (6/3)

For another participant learning disability nurses were the people who again provided medication when she was in short-term care:

> *'There's some nurses there and they give us medication on a morning and night-time and they're nice with us and I like it.'* (6/4)

In the final group of people with learning disabilities, this issue of medication also arose. One participant described his nurse as the person who:

'... does my medication for me. Makes me take different tablets, use whatever pills, antibiotics or whatever they are.' (1/9)

While at the day centre this group also appeared to have access to nurses and were available to help with specific health problems. One participant outlined the centre procedure: *'If you have a fit or anything like that then [Nurse 1] or [Nurse 2] would be there to make sure you're right'* (1/5). Another confirmed this:

'If [client] has a fit ... we always tell them. They can handle, help, in a simple way. We've got to tell [Nurse 1] and [Nurse 2].' (1/9)

This group also observed that some members of the day centre with more profound or multiple disabilities encountered learning disability nurses for specific purposes: *'They move certain limbs, when they get stiffness and what have you'* (1/12).

The participants referred to people with 'special needs' as being given *'plenty of help'* (1/13) by nurses, giving assistance with going to the toilet as an example. In another group, help with medication for people with special needs was also referred to:

'She looks after all the medication and all the people who can't walk.' (6/1)

However, it was also possible to identify other forms of support provided by learning disability nurses although these were also said to be provided by other professionals. One participant recalled that a nurse used to meet her regularly when she lived with her parents:

'This nurse used to come home with me every day to see mum and dad, then we used to go shopping in town.' (6/7)

Speaking of the present, another participant described the work and reasoning behind the involvement of one learning disability nurse:

'They go round the community helping one another and [nurse] also does something else with me when I wasn't very well. He took me to a football match. Plus some time ago [nurse] took me to town to see the ducks and that, and I really did enjoy it – it was great fun.' (8/4)

This participant also reported that the same learning disability nurse took him *'to the pictures sometimes'* (8/4). It appeared that another member of the group knew why the nurse did this:

'I know why. To get him out. To get him out to doing things in the community ... To save him being on his arse all the while.' (8/5)

He then explained why the same nurse occasionally took him out of the parental home:

'When you took me up them places and that, you took me out to relieve my mum and the pressure off my mum.' (8/5)

Later, one of the participants referred to a learning disability nurse as helping him to move from a day centre to local services:

'[He] helped me to start college and that he did. To help me learn at college a bit more ... He's the one who started me at college.' (8/6)

Another referred, somewhat obliquely, to problems that might arise if he did not see a learning disability nurse:

'I'd get run down ... I get shaky and that. I get shaky and that and I'd start talking to myself and I'd start throwing my weight about.' (8/7)

This group also commented that they would consult a social worker in similar circumstances. It is also important to note that one participant said they did not know what learning disability nurses did, *'I've got no idea'* (8/3). Others were more vocal and ended by

defining the role of learning disability nurses as *'they keep people well'* (8/11). Another noted that learning disability nurses would *'Talk about it … Talks to different people'* (8/11), and described how the learning disability nurse accompanied him to hospital. In broader terms one participant considered that a community nurse's role was: *'You look after the people … You look after the community, the people'* (8/11).

In other group of people with learning disabilities, the notion of the 'help' given by the learning disability nurse was unpicked. One participant described how her learning disability nurse:

> *'Helped me with things … when my mum started being poorly, my mum died, she helped me with that sort of thing.'* (6/2)

She reported that the nurse had helped her to get to see her sick mother in hospital, and supported her after her mother's death. Since then, the participant now in her late 40s and living in residential care, had not had a learning disability nurse because *'I don't need one now'* (6/2). Another participant recalled that she also used to have a learning disability nurse: *'I used to when I lived on my own. I used to have one a long time ago'* (6/3). Another participant had encountered nurses when he was in a long-stay hospital: *'I was in [hospital] for two-and-a-half years and I met a lot of nurses there'* (6/5). Another had spent a fortnight in hospital for respite care *'to give my parents a rest'* (6/5) and another knew someone who had also lived in the same hospital: *'He didn't like it. On a night-time people used to scream and shout'* (6/5). Here people used to have 'fits' and the nurses would help, *'The nurse makes it better'* (6/6).

One final example of the work of a learning disability nurse came from a participant who described how another nurse had erroneously said that a particular course of injections had not been finished when it had:

> *'Like when me and [nurse] went to get my injections, one of them tried to turn round and tell [nurse] and me that the next injection wasn't my last one. [Nurse] had words with her over it …'* (8/15)

Asked if he could have challenged the nurse himself, the participant, a man in his mid-40s living in residential care, said: *'I think I could have but I wouldn't have liked doing it'* (8/16).

4.3.1.2 The learning disability nurse as a friend

While many users saw the activities of the learning disability nurse primarily in terms of functional activities, others emphasised their personal relationship with a specific nurse. They saw their nurse as a trusted friend. One participant identified this 'friendship' in the leisure activities which his nurse undertook outside working time: *'He's very good he takes me to the pictures when he's got time'* (8/4). And later in the interview commented that *'I really am pleased with [nurse]'* (8/6) and *'I want to see him about with me a lot more'* (8/6). A woman aged in her late 30s living at home with her parents, reported that, *'[Nurse] took me to a lot of places and he's put himself out. He's put himself out in helping me'* (8/15).

In another group the personal qualities of the student nurses were remembered: *'You see you can talk to them and they'll talk to you and they're nice to get on with'* (1/6). And in respect of another student nurse: *'There was this one, she stayed up to the Christmas party, because we asked her to come'* (1/7).

4.3.1.3 Distinguishing learning disability nurses from other nurses

Having outlined participants' views of the tasks and roles of learning disability nurses, we now consider some of the other practitioners involved in individuals' lives to explore whether there appeared to be any distinctive positioning of learning disability nursing. One of the first themes identified was whether there was any difference between learning disability nurses and other nurses. One participant explained how he had encountered other nurses whom he described

as 'ordinary' nurses during a brief hospital: *'They just look after patients when they come round'* (1/5). Another participant gave an account of his visit to the local doctor's surgery where he was seen by a nurse when he had hurt his foot:

> *'She was telling dad what to do. You know just to get the stuff and put it on it to put the swelling down.'* (1/5)

However members of the same group said that the learning disability nurses based at their day centre would also be available for similar minor accidents: *'It's the same if you hurt yourself … [nurse] or [another nurse] would be there'* (1/5). In general, participants saw nurses positively: *'It was nurses make it work, make people better'* (1/7). But they could be differentiated by their uniforms. One participant said: *'They've got different uniforms'* (1/8) and another confirmed they 'sometimes' wore uniforms (1/8). This was in contrast to community-based learning disability nurses (8/10).

In a group of people with learning disabilities there was some indication that the role of the learning disability nurse was different from that of other nurses:

> *'A nurse's job is to help people to do things for them and that and everything. And [nurse]'s job is not to give me an injection – it's a nurse's job … [nurse] [has] done a lot of things for me.'* (8/6)

In this group hospital-based nurses were also remembered as 'sisters' and 'staff nurses' (8/8). Nearly all the participants said they had had their wisdom teeth extracted in hospital. Such nurses' activities were described as 'giving me the anaesthetic', taking blood and recording blood pressure. This work was described by one participant as *'they look after people and make sure they're alright'* (8/8). One individual commented *'their job's harder'* (8/8) and that *'They knew their job'* (8/10).

Participants also had personal experience of nurses other than those based in hospitals. Many, with ageing parents, had encountered community nurses providing support or treatment to family members. One described how his mother visited a nurse in connection with her diabetes: *'She asks my mum how she is and takes her blood pressure and everything'* (8/12). In another interview, one participant outlined her experience of Macmillan nurses caring for people with terminal illnesses:

> *'In their own home they look after them. I know about them. My mum died last year and I know a bit about home-care, nurses coming and helping you out, getting them out of bed and dressing her and that.'* (6/3)

Another participant voiced similar experience:

> *'My dad came out of hospital and the Macmillan nurse came every day to look after him. They told my mum, at the hospital, that he hadn't long to live and then he came home and the Macmillan nurses came.'* (6/3)

4.3.1.4 Perceptions of other health professionals

Not surprisingly many participants had encountered a variety of health professionals across the years. People were familiar with their own GPs (1/6) and with other doctors visiting establishments such as day centres: one participant, referring to such doctors, described their visits as: *'Someone comes around with forms to fill in'* (1/8). Within places such as day centres other professionals were also encountered: *'We have speech therapy here … Helps me learn to talk properly'* (1/9).

In one group all participants were familiar with occupational therapists, physiotherapist, psychologists, doctors and psychiatrists. Over the years many had attended surgeries and hospitals for physical complaints.

Within some groups participants were in regular contact with social services personnel through accommodation services. One person, living in sheltered housing, felt she had sufficient and adequate access to social services support:

> *'I've got people down at [SSD] and if I need them anytime I just have to ring and they'll come.'* (6/6)

Another participant provided an account of her short-break care in a residential unit where the staff appeared to be comprised of nurses providing daily medication and care staff who were engaged in more social activities:

> *'They take us shopping on a Monday, they let us go watch swimming on a Tuesday, Wednesday we have a game of bingo and Thursday they do Trivial Pursuit and that. Friday they take us out for a drink and next year they are taking us on holiday to Majorca.'* (6/4)

For those living at home, support was provided by 'care workers' from 'social services' (6/5) and one participant explained this role:

> *'What [he] is saying [is] they help support them live in the community. Trying to help them, eventually independent living.'* (6/5)

Most seemed clear that nurses did not help with this type of practical support (for example, shopping) but in some groups there was confusion between social workers and learning disability nurses. In one group, participants said they would see social workers if there were no learning disability nurses and they were getting into difficulties. However there was understandable confusion between different professional roles:

> **Interviewer:** *'What's the difference between them?'*
>
> **A:** *'They're not nurses.'*
>
> **J:** *'They're doing different subjects to one another.'*
>
> **Interviewer:** *'Can you give me an example?'*
>
> **J:** *'Well, [nurse]'s got a much ... a much harder job than [social worker] and he's got a lot more responsibilities than her ... like looking after people ... He's higher up than her ... he's a different grade.'* (8/5)

In these interviews the term care manager was not used or prompted.

4.3.1.5 Teamwork

The focus group discussions briefly explored whether the concept of or term 'community learning disability team' was familiar. In one group other learning disability nurses were mentioned as part of the team:

> **A:** *'I know [Nurse 1].'*
>
> **Interviewer:** *'What does [Nurse 1] do then?'*
>
> **A:** *'Talks to people.'*
>
> **Interviewer:** *'The same as [Nurse 2]?'*
>
> **Group:** *'Yes.'*
>
> **J:** *'And there's also someone else, who's also a community nurse ... she gets around the community and that and starts doing things.'* (8/15)

In another group there was no direct discussion of the team but one participant referred to his knowledge of such a team: *'We know that, don't we?'* (1/8). The final group identified social services as a base that they could access by telephone if they were in any difficulty.

4.3.1.7 Comment

Nocon and Qureshi (1996) suggested that the way a service for people with learning disabilities, such as community care, is delivered is an integral part of the service, and considered that this might be more so than in health care. The data reported above provide evidence to confirm that process is an important feature, and that some service users consider it vital to health care. As they noted many of the long-term needs for people with learning disabilities are for social care rather than medical services, but our data suggest that community health services remain an important part of community living. People with learning disabilities appear to have their health care shaped by professionals, possibly because they are not encouraged to manage their own health needs. The mediation role of nurses is thus an important part of how people access health care. Our data also showed that it is not only learning disability nurses who work with people with learning disabilities. Nurses in all locations need preparation for working with people with learning disabilities.

Our interviews indicated that service users valued practitioners who had a human face, rather than assuming technocratic or bureaucratic identities. In terms of quality indicators their perceptions were similar to those advocated by a group of parents interviewed about short-term care for their disabled children. Russell (1996) summarised these as:

- being local and accessible
- providing good care – not medicalised but not ignoring special needs
- available on demand
- being integrated with other support.

4.3.2 Families' perceptions

The five remaining interviews are considered together, although in one focus group two participants were people with learning disabilities. However in this interview discussion was dominated by family members. It should be noted that all family members in these interviews were parents and most shared their home with their adult children who had learning disabilities. There were two married couples and most were approaching or had reached retirement age. The material from the interviews is presented in similar themes corresponding to those that emerged from the groups composed of people with learning disabilities.

4.3.2.1 Recognising the role of the learning disability nurse

Many, but not all, participants who were parents had experience or contact with learning disability nurses. For some this extended to years of accumulated experience. Others had briefer or intermittent contact. Some would have liked contact currently or felt it might have been beneficial in the past. These opinions are illustrated through participants' own words. For example, one mother of a young man with learning disabilities living with her at home, did not recognise the term or idea of an learning disability nurse:

> *'No, no, I've heard of community health nurses and I assume that's the sort of person you're talking about. I've no recollection of them at all. Even though I presume [son] is on one of the lists.'* (5/2)

However, this was challenged by another member of the group, who reminded her that learning disability nurses had been involved in setting up the group:

> *'But, to be fair, the group formed because of the community team nurses that used to be based here. They suggested that we start up a support group ... so, we came about from that ...'* (5/2)

In the same group the mother of a young girl with multiple disabilities also recognised the term:

'I have one for children, a children's learning disability nurse. They specialise in that. But I haven't seen him for about 18 months [everyone laughs], despite requests.' (5/3)

In contrast an older mother reported that she had been in contact with a learning disability nurse for some years.

'In my experience, I found them very helpful. I lost my husband five years ago and this was introduced for me … And also, we had a gentleman who was a nurse [and] introduced a counselling for bereavement for learning disability, which was a great help for [son].' (5/3)

Another positive experience came from a mother of a child with disabilities: *'She was absolutely wonderful. She was the children's community nurse'* (5/5).

This variety of experience was repeated in other groups from different parts of the country. In some areas, service changes had involved a fusing of care management and learning disability nurse roles. One participant was now not clear about the professional status of her daughter's care manager:

'I mean I've had a new care manager but I don't know what she was, what she is to be honest. I know her name, that's all I know.' (2/1)

Another participant explained:

'I think the overall title care manager encompassed social worker and learning disability nurse but it gave them a wider perspective on being paid by one group rather than being paid by social services and health. It just gave them a different title to do the same job.' (2/2)

However, participants outlined that in their experience learning disability nurses possessed particular skills in some areas:

'My son suffers from epilepsy and the nurse was experienced enough to do it anyway. I think if you're talking about medication, changing medication, tablets, or whatever, then the type of fit, then she was actually there with you and could actually understand exactly what you're talking about.' (2/4)

Another mother added:

'I mean she very much took on a behavioural role when we have behavioural problems within the home, she could come in and help with those too.' (2/4)

This discussion pointed to the wider range of skills and experience possessed by learning disability nurses. One participant viewed this as beneficial:

'I think if you look at it, it stops another team, another person coming into your home which I think as parents or carers we felt like we're a bit like Victoria Station, you know we'd have so many people coming in providing some service or another.' (2/4)

In her opinion there was less need to repeat or duplicate history and for parents to educate practitioners who were unfamiliar with the subject. Medication again provided an example of a matter about which learning disability nurses often knew far more than social workers or teachers:

'… because they've got no nursing background, so they haven't really got a clue, you know, about why they have to change from this medication to this one or whatever.' (2/5)

Other participants also considered that learning disability nurses were better informed about other matters such as benefits than other professionals who had to be taught as:

> *'They're also not aware of all the sorts of things you're entitled to – benefits, or anything like that, so we're teaching them half the time.'* (2/4)

In this group learning disability nurses were characterised by both wider: *'knowledge, experience'* (2/11). Thus, rather than classifying nurses' help as solely high-level treatment or quasi-medical intervention, participants recognised that learning disability nurses possessed greater liaison skills in relation to their own needs but also in respect of people with learning disabilities. In essence, learning disability nurses were specialists who could help family members, particularly parents who regarded themselves as very much the experts.

4.3.2.2 Family focus

In addition to the experience acquired by learning disability nurses in working with people with learning disabilities, a number of parents spoke of them as possessing skills in working with parents or families. These ranged from liaison or co-ordinating skills to direct quasi-therapeutic help or support for carers at an emotional level. As the mother of a daughter who had died in early adulthood commented: *'I mean mine was my rock, I have to say that, absolutely my rock'* (2/7). Another parent described the support received by the whole family:

> *'Well really you're able to offload the baggage, problems and emotions that you were going through, they became a mediator between whatever was happening, as well as your sons or daughters, they'll be there to sort out a care plan … they became very much a crutch I think for your survival to be quite honest.'* (2/7)

This notion of being available to the family was reiterated by other participants: *'They almost become a care manager to the family, don't they?'* (2/7). In this group the dual focus of the learning disability nurse was greatly appreciated: *'they weren't just there for your child if you wanted, but they were there for you '* (2/7). As an example of what this meant in practice, one mother reported a high level of engagement:

> *'She gave me more than I ever thought she would. She gave me her home telephone number, she trusted me.'* (2/7)

Another felt that there had been an intuitive recognition of her needs as a carer:

> *'I know that ours would pick up the phone and say how are you? [I'd say] "Well, we're fine," [she'd say] "No, you're not," because they would detect that in your voice and "I'll be over" and that's the closeness.'* (2/9)

This level of personal contact was important to this group. The learning disability nurse appeared to have communicated her concern for the family and mother in particular. This was reassuring, promoting feelings of trust and security. In contrast to social workers, as we describe later, parents felt that learning disability nurses were not so likely to be judgemental or to invoke the spectre of child protection (2/7).

4.3.2.3 Vocation and personal characteristics

Just as some users saw learning disability in personal rather than just technical or activity terms, so did family members. However while users tended to see these personal aspects in terms of friendship, family members saw it in terms of vocation.

Some considered it was not easy to enter learning disability nursing, *'I'm not sure it's easy to become a learning disability nurse because of the background you need, the selection process, the training and things'* (2/12). Individuals who did so had to be committed, *'that's what they've chosen to do, so it's a calling or vocation if you like'*. Another participant reflected a similar view:

'The income they're going to get is pretty poor, so why do they go in it? It's because that is the work they've chosen, they like it, they enjoy it, they want to make a difference.' (2/8)

This matter of vocation was important to families:

'So you know immediately that the person you're meeting has chosen to go into the learning disability field which immediately gives you that common bond.' (2/16)

Another spoke of being able to 'detect' whether a professional could relate to people, another saw this quality as 'empathy'. The choice and interest of the learning disability nurse was contrasted to other nurses' ignorance at times and society's indifference or prejudice, *'this society thing of "oh, I don't want to know"'* (2/17). Nurses understood parents' position, so that, while a social worker:

'... would switch off when the doors close at five ... the nurses seem to realise how quickly you needed the response.' (2/18)

In one interview, a mother reflected on the difference between learning disability nurses and the other professionals she had encountered. In her view it was connected with attitude as well as experience and knowledge:

'I think it's confidence that they instil in you and your son or daughter. And I think it's the naturalness with how they approach you, as though everything is just on an ordinary scale, no matter what the problems are, you're not made to feel different or any more different than necessary when dealing with problems. I think the way they approach you, the naturalness and the confidence they instil.' (3/6)

In another focus group, parents referred to their relationships with learning disability nurses as *'far more relaxed and informal'* (5/11) than with other professionals. This again was connected with their choice of work:

'... because our children have learning difficulties a lot of people think that we automatically have learning difficulties as well. I think that's probably the difference because they've chosen that ...' (5/12)

This notion of vocation was all the stronger because, in contrast, other professionals, as two mothers commented:

L: *'... are frightened of working with our children, because they're unpredictable and they don't act as expected, you can see, you honestly can see the fear in their eyes.'*

M: *'Yes, I've had that.'* (5/13)

4.3.2.4 Comparisons with other nurses

One of the perceived advantages of being in contact with a learning disability nurse compared to other nurses was that learning disability nurses possessed specialist knowledge. As one mother of an adult living at home said of her contact with a learning disability nurse some years previously:

'I think from what I can remember they knew more about what our difficulties were than a general nurse would.' (4/5)

This specialist knowledge equally applied when the learning disability nurse was compared to other nurses in hospitals:

'They [learning disability nurses] might realise that it takes our children longer to do something. When my son was in hospital and he had stuff on

his chest, they kept saying cough it up and spit it out; my son can't do this. A learning disability nurse would understand this and might take a bit more time and trouble. Because they won't do things straightaway.' (4/5)

In another group, one participant explained that it was training which equipped learning disability nurses to be more effective:

'Well they are aware of learning disabilities and sort of what's caused by brain damage, which is behavioural, which things you can modify, which things you can't, those sorts of things. Although as parents you soon get to realise what you can change and what you can't. You can speak to them and they will understand what you are getting at.' (7/2)

This experience and knowledge set them aside and made them useful and more relevant:

'Because they've come across lots, their expertise and experience would be far wider … whereas an ordinary nurse might have come across a few children with learning disabilities but the vast majority of their patients won't have.' (7/2)

It was the scale and accumulation of experience that appeared significant:

'It is very useful having someone who has got real experiences, day after day, of people with learning difficulties.' (7/2)

Using concrete examples, parents spoke of their feeling that this specialism allowed learning disability nurses to explore health issues but also to relate health matters holistically to a person's wider needs:

'I think we've had help with regards [to] respite care for my daughter and the community nurse was very, very helpful in the assessment of her medical needs and possible future needs she may have regarding her drugs and medical condition … there are so many things that interlink when a person has a learning disability as well as having health problems. So it was useful because she asked from all sorts of sides.' (7/2)

For parents this breadth of understanding was not always evident among other nurses. One mother of a young man in his early 20s living with her at home spoke about the chance meeting with a general nurse who was exceptionally helpful in a general hospital setting:

'There was one young nurse that was good and … she popped in from time to time … she had a relative who had a Down's syndrome and a disability, so they thought she was used to that …' (3/3)

Finally, parents were not clear about whether school nurses, particularly those working in segregated or special schools, were learning disability nurses. Nonetheless they often voiced considerable appreciation of their role, for example, one mother reported:

'They were excellent. Both in and out of school they were excellent at passing information on and things like that. But it would appear that there seems to be a split depending on where you go, because since [son] has left school everything seems to have fallen apart, not just the nursing.' (5/5)

4.3.2.5 Contrasting nursing with social work

In analysing the data to establish participants' perspectives about social services it was important to distinguish between services commissioned by the local authority SSD, the representatives of this department, variously called social workers or care managers and the services provided by other agencies but organised or paid for by social services. Parents equally had experiences of a multifaceted NHS but social services were particularly complex.

For some older parents the relocation of services in respect of their children from the long-stay mental handicap hospital to social services provision represented a move away from a service that had inspired security. This world had been peopled by nurses. One mother recalled a painful episode when movement from hospital to a home appeared to her to have been badly handled:

> *'But I think, maybe you [facilitator] ain't nowt to do with social services, they did a dirty trick on us … Social services just said she'd [daughter] had to go. [Official] said they wouldn't have to send her but they did and I just sat and I cried about it that day … So I've never had much faith in social services since that.'* (4/3, 4/4)

In another interview a mother discussed her similarly negative experiences when the local respite unit moved from the NHS to social services control, *'quite frankly there's been nothing but trouble since they changed'* (2/3). In this group, however, other participants considered that these changes of provider were familiar tussles over territory as this debate illustrated:

> A: *'Yes, but isn't this about the practice of providing, and about who provides what, whether it's social care or nursing care … It's who picks up the tab isn't it, that's what I'm trying to say.'*
>
> B: *'But on the ground, the child is still having the same needs, but basically being messed about.'*
>
> C: *'… I mean it's a hot potato with disabilities – they throw it from one to the other.'* (2/3)

This frustration with two separate agencies was not generally mirrored by criticism of individual practitioners. However, some participants considered that generic social workers or care managers lacked expertise in learning disabilities:

> *'No disrespect, but someone from social services and this [learning disability] is part of their remit, then that's not what they've chosen to do. I don't see how you can give it that 100% the community nurses gave.'* (2/4)

Another participant thought that this lack of experience made such a practitioner *'quite unsure of yourself – we've had people who've said, well what happens now?'* (2/4). Other mothers commented:

> C: *'That's an experience thing.'*
>
> D: *'Absolutely, that's right, but I don't think, with great respect, with great respect to them, the social worker has got [it].'* (2/5)

This group gave an example of the benefit of experience:

> *'When you know this individual and you know that the mention of the word [drug], will send them into complete panic, then you know already you've done something that's going to cause problems and repercussions somewhere all the way down the line. Because I've been there, I've seen that happen.'* (2/5)

In this interview, parents were critical of the organisation of social services, which seemed to change frequently, meaning there was little continuity of support for them:

> *'Years ago they seemed to stay in the job longer, you're also talking about continuity of staff, are you going to trust somebody, you need to know them a long time. Quite frankly, we seem to see a care manager for about six months and then they're gone.'* (2/8)

Other participants confirmed this:

> B: *'We've had two in the last six months.'*

D: *'We've had [Care manager 1], but she's gone and the helpline is useless, and now we've got [Care manager 2].'* (2/5)

However, one participant felt she had been fortunate:

'Our social worker has, she's worked in the learning disability field and been the manager of a learning disability unit, so she has got that knowledge ...' (2/8)

This, she felt, was exceptional. The key difference with social workers, as another participant put it, was their lack of experience in providing hands-on care: *'What's a social worker? They've never cared or looked after them anyway'* (2/8). Even the mother who considered herself fortunate (above) considered *'they're still very different, totally different people'* (2/8). For another mother this was possibly because social workers were associated with child protection:

'Don't you think that's part and parcel, of something that tells you if they've looking for some hidden agendas, because that's what social workers do ...' (2/8)

Another later acknowledged that this might be a matter of perception, *'I th. ik it's the perception that some people have, don't you?'* However for another mother social workers were more intrusive and judgemental:

'People coming into your home and checking you're doing everything as you should be doing it and there's nothing untoward, it's wrong.' (2/9)

In this group, mothers considered they possessed greater expertise than their care managers and that their parental networks were more reliable: *'It's more by word of mouth between mums than it is between care managers'* (2/10).

4.3.2.6 Comment

These carers presented a picture of a complex organisational world in which organisations, terminology, professionals and services were subject to frequent change. This affected whether they recognised learning disability nurses among the many professionals they had encountered over the years. Their difficulties in conceptualising the role of learning disability nurses reflect the limited contact of such nurses with carers overall. A variety of research continues to confirm that many families receive little support. Nearly 60% of all carers receive no regular visits from any services, despite their desires to share responsibility with service providers (HM Government, 1999). As some carers indicated in the focus groups, they were often in need of support from primary care services in general and over specific matters. This confirms Langan et al.'s (1994) survey where many carers reported 'feeling at a loss' over behavioural problems, communication difficulties and medication. Further calls for advice on medication continue to come from research into the needs of carers (e.g. Goldstein and Rivers, 1996), while the Carers' National Strategy (HM Government, 1999) reported that 94% of carers need help to ensure that the person cared for takes medication. Such findings have particular significance for learning disability nurses, who are educated uniquely in respect of medication and its relationship to psychosocial wellbeing.

The focus groups provided some evidence that families conceived of themselves as having needs different from those of people with learning disabilities, confirming a growing appreciation that user and carer perspectives may legitimately be distinguished. Such a view has tended to be voiced by disabled people, but it was clearly evident here when carers spoke of their wish for some professionals to be more family focused and praise for those who responded to families' concerns. While many commentators write of the 'success of the carers' lobby' (e.g. Barnes, 1997) our respondents did not appear to share this notion of victory. They still reported difficulty in accessing services for themselves or the cared-for person. While much research and good practice continues to argue for 'key' co-ordinators to help families through the service maze, our research indicates that many families negotiate their own pathways. Finding a helpful,

accessible professional, of whatever kind, appears to be some families' response to the deficit on 'key' workers: in a sense they try to create their own.

The group interviews suggested that community-based care for families was associated with systems of care management, and families correctly acknowledged the lead role of SSDs in commissioning any such services. Few were able to map community-based learning disability teams, and many remained suspicious of social services as agencies concerned with abuse and protection. Our interviews were with people who were in contact with services and so we were not able to confirm whether such perceptions were held more widely. However, the groups appeared to accord high value to individual practitioners' abilities to forge relationships with families, and this paralleled the views of people with learning disabilities.

Both users and carers base their accounts of learning disability nurses on personal experience, and both groups are aware of and appear to value the distinctive role. In some cases they emphasise the value of learning disability nurses by contrasting their understanding with the technical but impersonal competence of general nurses and even 'horror' stories of the lack of understanding and empathy of some professionals. They see the distinctive role of learning disability nurses both in professional terms, especially knowledge of and skills providing support and care and in personal terms. For users this is the 'friendship' provided by individual nurses and for carers it is the 'vocationalism' of learning disability nurses.

4.4 Users, families and education

Chapter 6 considers users' and families' evaluation of nurse education and in education, and Chapter 5 considers in detail the values, knowledge and skills underpinning nurse education. In this section we examine the importance that the designers of educational programmes attach to users and families and the ways they have sought to involve them in the programmes.

4.4.1 Importance of users and families: evidence from programme documents

4.4.1.1 Users

In all the documents analysed, users were the prime focus. It was clear that designers saw their programmes as ensuring that future nurses would be aware of and could meet the needs of carers. This was particularly evident in pre-registration programmes. The main aim of a diploma programme was identified in the following way:

> *'The client groups that the student will care for is heterogeneous, ranging from preconception to death and existing within a multiracial and multicultural, dynamic society. We value the differences and equalities between and within people and client groups.*
>
> *The learning disabilities branch will provide students with skills appropriate to a wide variety of care settings and will reflect the changing care provision for people with learning disabilities across an age continuum.'* (Pre-registration diploma programme)

One BSc programme, which prepared students for Part 14 of the Register, provided a particularly comprehensive specification of the centrality of users. The programme team incorporated the clients' charter developed by local NHS service providers:

> *'Both the team and the [Trust] share the belief that service providers and staff should be committed to understanding and meeting the unique needs and wishes of each service user through health and social support services, in co-operation with other agencies and the community. These are reflected in the 'Client's Charter' created by the Trust, which guides Trust staff and students on placements in their practice:*

THE CLIENT'S CHARTER

We aim to continually improve the quality of life of people within our care. The Client's Charter contains the basic values underlying our services:

- *Each client is to be treated as an individual*
- *Each client is to be treated with respect and to be given the opportunity and support to present themselves with dignity*
- *Each client is entitled to be given the opportunity and support to make choices and be involved in decision making*
- *Each client is entitled to continuity and progression through the different stages of life*
- *Each client is entitled to a network of friends, the opportunity and support to remain in contact with relatives, and the opportunity to develop deeper relationships*
- *Each client is entitled to live as part of an ordinary community taking full advantage of local facilities*
- *Each client is entitled to opportunities to develop skills and support in minimising their disability*
- *Each client is entitled to professional services aimed at maximising physical and mental health, comfort and safety*
- *Each client is entitled to an advocate or representative who is not in the employment of the services*
- *Each client is entitled to receive a professional service that identifies its aims and constantly monitors how well it meets those aims and addresses any shortcomings.'* (BSc pre-registration programme)

4.4.1.2 Families

While users formed the central focus of programmes, families were less frequently and less explicitly identified; in some their interests were not separated from those of service users. When families and other informal carers were identified they tended to be grouped with either clients or with professional carers. For example, in the following pre-registration programme professional and 'lay' carers were grouped together:

> *'This programme will prepare practitioners to take on new roles and carry out a broad range of tasks [and will] prepare safe, competent practitioners capable of delivering skilled, thoughtful and compassionate care in a wide range of health care settings, and in collaboration with professional and lay carers in state, independent and voluntary agencies.'*
> (Pre-registration diploma programme)

In the following extract from the documentation of a pre-registration diploma, families are grouped with 'significant others'. The aims include to *'communicate effectively with clients, families and significant others in a range of settings'*. An equivalent programme groups families with 'communities':

> *'The role of the nurse is supported by a caring ethic which incorporates the desire and maturity to help individuals, families and communities in need of health care and support.'* (Pre-registration diploma programme)

4.4.1.3 Involvement in programmes

There was some evidence that users were involved in not only the design but also the delivery of programmes. In one joint social work and nursing pre-registration programme, the development team included representation from: service providers, service purchasers, service users, carers, education, social work, nursing and management, independent and public sectors.

While participation was well developed in pre- and post-registration programmes, it was also evident in specialist programmes. For example a specialist forensic programme indicated that there was *'client participation in evolving standards'*, that they encouraged *'the contribution of client and carer'* and that the reading list suggests reading material written by users and carers. Similarly a post-registration programme specialising in violence and aggression indicated that, *'service users are actively involved in the development of our programmes'*, and that *'increasingly, service users are actively involved in the delivery of our programmes'*. A similar programme emphasised that, *'the team also wish to ensure that the user's perspective is taken account of in the planning of this programme'*.

While most programmes made general reference to the involvement of users and families in programme design and development, only exceptionally did programme documentation provide detailed information on their role. However in the following extract from a degree-level social work and nursing programme, there was a detailed description.

> *'The programme is actively promoting the involvement of people with learning difficulties in its teaching. This is being achieved by working with members of local advocacy groups and their supporters.*
>
> *The [group involved in the programme] was formed in 1995 and includes representatives from [local advocacy groups]. The group meets to plan their sessions with the students, develop new ideas, and discuss their experiences of working with the students ...*
>
> *The group will be involved in*
>
> *Placement Preparation during the Common Foundation Programme for Learning Difficulty placements;*
>
> *Theme days during the 3 year period of the programme;*
>
> *Co-teaching with lecturers on particular aspects of working with people with Learning Difficulties.*
>
> *Module XX – A person with learning difficulties will co-run the session on parenting.*
>
> *Philosophy – The commitment to the value of collaboration must extend beyond the relationship between professionals in services and education, and include finding mechanisms to involve people who use services in both the assessment of students practice, and at the point of curriculum design and delivery. The programme is committed to such involvement and works in partnership with local Advocacy groups.'*
>
> (Combined nursing and social work degree programme)

4.4.2 Involvement of users and families in the design and delivery of the curriculum: evidence from lecturers

In addition to analysing programme documentation we interviewed the lecturers responsible for 12 pre-registration and post-registration programmes. We asked them about the design and delivery of the curriculum. Only one lecturer responsible for a pre-registration programme spontaneously mentioned the involvement of users and carers in the design of the curriculum, and even in this instance it was a voluntary agency, Mencap, rather than individual users or carers:

Lecturer: *'My predecessor was heavily involved in designing the curriculum along with [name], the professional leader for learning disability lecturers in the department. With them was the social services training agency, so social services consortium were involved and the local NHS trusts and I nearly forgot, Mencap who are partners in the arrangement so we've got four partners I suppose in the scheme. There's clearly the university, there's Mencap, there's the trust and there's social services training agency and all of those bodies were involved.'*

Interviewer: *'How would parents be represented. Is that sort of seen as through somebody like Mencap or the Mencap officer?'*

Lecturer: *'Yes, we don't have direct input from parents.'* (Pre-registration diploma programme)

When the other lecturers were prompted only two explicitly stated that users and carers were not involved in the design of the curriculum. For example, the lecturer responsible for a post-registration programme focusing on people with learning disabilities and mental health needs described the development of the curriculum in the following way:

Interviewer: *'Who was involved in the design of the curriculum?'*

Lecturer: *'There's myself and a psychologist. Also a psychiatrist and there was a nurse who I liaised with in relation to [mental health] … Somebody else who worked in the field of dual diagnosis who I used for consultation purposes, you know – "what do you think?" "Do you think this will work?" etc., etc.'*

Interviewer: *'Was there ever any contact with service users?'*

Lecturer: *'Not in the designing of the curriculum, but obviously there were service user issues that triggered the development of some of those things. In relation to service development I like looking at individual packages.'* (Post-registration programme in learning disabilities and mental health)

The other lecturers acknowledged that users or families had been involved in the design of the curriculum. One lecturer responsible for a diploma pre-registration programme commented:

Interviewer: *'Can you tell me how the curriculum was designed?'*

Lecturer: *'Right, way back in '93 what we did was get together service representatives, members of staff, students who were on a previous course and just get down and see what was required. Really looking for what the service was requiring user from the students in terms of when they qualified.'*

Interviewer: *'Right, you've already mentioned that you had service users involved …'*

Lecturer: *'Yes, yes, yes, there was some user input but I think you'd maybe find now it's quite difficult to maintain that kind input, but yes, there was some at the time.'* (Pre-registration diploma programme)

The majority of the lecturers involved users or families in the delivery of the curriculum; however they clearly felt some anxiety about 'tokenistic' involvement. Students would get an opportunity for 'real' contact with users and families when they did their practice placements. For example, a lecturer on a pre-registration programme referred to contact in class in the following way:

Interviewer: *'In the teaching do you involve service users or carers?'*

Lecturer: *'We have attempted to through a couple of advocacy groups which we linked in across the city but more often than not you tend to find it is the advocacy worker who does the work with the client, with the students as such in the workshops and so forth than the actual client. So there has been a little but you could almost argue that it's very tokenistic in terms of the clients' contact with students.'*

(Pre-registration diploma programme)

A lecturer on a specialist practitioner programme described the involvement of a parent in a specific teaching session, but it was clear that this session only formed a small part of the overall programme:

Interviewer: *'Are any users and carers involved in teaching?'*

Lecturer: *'There is one session where I bring in a carer to talk about her experiences of service provision. She actually lost a child. She had a child who was profoundly learning disabled who died several years ago and she has quite comprehensive experience of service provision – not all of it very positive, but I think that it puts it in context for when you take ethnic minority care, single parent care and things like that – it brings it all together. She only does a 45-minute session followed by questions.'* (Post-registration specialist practitioner programme)

In interviews with current students, none of the groups identified any sort of involvement of people with learning disabilities or carers in the class room context. Only one group referred to them, commenting that no users or carers were involved, but they *'should be though. It needs to be changed'* (2/4).

Lecturers clearly felt that the design and delivery of programmes was and should be dominated by practice and professional concerns. When explicitly questioned about the role of users and families, most agreed that they could and did play a role in the design and delivery of programme, but it was clear that this role was limited and some even described it as tokenistic or the 'flavour of the month'.

4.5 Summary and comment

The focus groups with carers or parents provided a rich seam of data, particularly in their discussions of the role of the learning disability nurse as a source of expertise and support. Most users and families were clearly able to articulate their views of learning disability nurses based on their personal experiences. They generally commented favourably, contrasting the expertise and caring approach of learning disability nurses with the narrow technical expertise of general nurses, or recounted 'horror stories' of the uncaring and negative attitudes of some professionals that were combined with an ignorance of learning disability. The changing attitude towards people with learning disabilities and their families has been reflected in a concern to access their view and to involve them in the planning and development of both services and education. While programme documentation indicated that users and carers were involved in the development and delivery of the curriculum, lecturers indicated that their involvement was more restricted and they were not systematically involved in the development of the educational curriculum or the delivery of programmes.

5.1 Introduction

In this chapter we explore the ways in which educational institutions approach the task of preparing nurses for practice. We set the context for this discussion by looking at the general development of teaching strategies in nursing. We then consider the general design of the nursing curriculum using evidence from our analysis of programme content. Finally, we consider tutors' and students' perceptions of the ways in which the curriculum is actually delivered.

5.2 The development of nurse education

Until the 1990s the majority of education was provided by schools or colleges of nursing that were part of the NHS, and both tutors and students were employed by the NHS. As Meerabeau (1998) pointed out, different types of nurses, such as mental health or learning disability nurses, trained separately in 'schools' located within their own specialist hospitals.

5.2.1 The changing location of nurse education

Nurse education can be defined as the *'theory and practice of nursing and the acquisition of skills'* (Phillips et al., 1996). The early development of nurse education was heavily influenced by Florence Nightingale, who established the first training school for nurses in 1860 (Hector, 1973). As a charismatic personality she saw herself as the leader of a social movement, referring to nursing as a vocation and even a religion (Hector, 1973). Training was designed to provide future leaders of the movement, modelled on, supported and controlled by its founder. Thus the central feature of training was the socialisation of the 'probationers'.

The legacy of the Nightingale reforms was a system in which the prime emphasis was on instilling predefined values and skills in trainees by working alongside experienced nurses on hospital wards. This approach is often referred to as the apprenticeship model; training was:

> *'... usually associated with a well-defined course with a definite end point and with an emphasis on the development of certain pre-defined skills ... [The aim of the training model was] to produce a "standard nurse" who has certain skills and abilities that have been identified for her prior to her commencing the course.'* (Burnard and Chapman, 1990: 37-38)

One consequence of this approach was an under-valuation both of the knowledge base of nursing and of nurse teachers who were responsible for developing and transmitting this knowledge. The Salmon Committee, which reviewed the structure of nursing in the 1960s, identified considerable dissatisfaction amongst nurse teachers stemming from their subordination to nurse administrators and their lack of control of 'practical instruction', which was undertaken mainly by ward sisters and nurses (Ministry of Health, 1966).

Criticisms of this apprenticeship-style research were still evident in the late 1980s:

> *'RGN courses ... were based on an apprenticeship-type model with much reliance upon experience gained in the clinical setting as a means of acquiring knowledge and skills. The adequacy of this model with its assumption that trained nurses would teach and supervise student nurses has been questioned.'* (While et al., 1995: 4)

There was also concern that students' opportunities to learn were limited by the pressure and workload of clinical staff for whom teaching was a low priority.

One response to the poorly developed and undervalued theoretical knowledge base of nursing was the development of nursing departments with the capacity to undertake nursing research and use this as the basis of student education. Following the establishment of the first nursing degree at the University of Edinburgh in 1960 (Altschul, 1987), a number of educational institutions followed this example.

The growth of degree programmes resulted in tension between the new graduate nurses and traditionally-trained nurses. Traditional training stressed the primacy of practical nursing skills and socialisation into a strong clinical or ward culture, which was often associated with an uncritical acceptance of task-orientated nursing. Graduate nurses did not feel part of this culture and were interested in a more patient-centred style of nursing. They were seen as 'high fliers' who acquired a minimum of practical experience before moving up into managerial posts (Phillips et al., 1996).

5.2.2 Student-centred learning

The development of university-based education and the view of students as learners rather than 'an extra pair of hands' has resulted in a changing approach to both teaching and learning. In traditional classroom-based teaching, students were treated as passive recipients of teaching *'as if they were bowls waiting to be filled with core content'* (Boyer, 1999: 116). This could work in the 19th century, when knowledge and skills were seen as relatively static and the main value being inculcated was obedience to authority. However, modern practitioners are being prepared to work in a changing environment (Allen, 1997). To achieve this flexibility, they need the ability to change their own skills to match the changing needs of practice and service users. Thus practitioners need to play an active role in the learning process as they need to be able to learn without the support of the teaching institution. As Macleod Clark et al. (1996) noted, this commitment to lifelong learning underpins nurse education in general and pre-registration programmes in particular.

The emphasis on the active, even leading, role of the student in the educational process has resulted in a shift of focus from teaching to learning. For example, Rogers defined education as *'planned learning, contrived and purposeful learning opportunities'* (Rogers, 1986: 10). He viewed education as an interactive process in which both teachers and learners need to contribute to defining aims and structuring opportunities and both should learn from successful education. Rogers contrasted open, co-operative forms of education with closed authoritarian styles in the following way:

> *'At one end [of the spectrum of educational styles] are those planned episodes with narrow goals, the aim of which is to demonstrate that there is a "right" way to do something or other. These are largely in the skills area but not entirely so; some people are taught that there are "right" ways of understanding, or behaving and even of learning. Choice is strictly limited and not encouraged. This is what we usually mean when we speak of training. At the other end are all those activities that set out to convince us that there is a "right" way of thinking and feeling. Once again there is a limitation, even a denial, of choice; there is only one way to think, one set of values and attitudes to hold ... indoctrination.'* (Rogers, 1986: 15)

Jarvis (1985) analysed the educational process in terms of polarised ideal types, variously referred to as: classical or romantic; continuing or recurrent; education from above or education from below; and pedagogic or andragogic. He identified four assumptions in the pedagogy versus andragogy debate. In the pedagogic approach, the learner is dependent on the teacher, his or her experiences are not valued, the curriculum is set and standardised and the main emphasis is on the acquisition of subject matter by the learner. In the andragogic approach, the learner is encouraged to be self-directing and move towards independence, the learner's

experiences are valued and treated as a rich resource, learning is orientated towards the knowledge individuals require and the learning experience is problem-focused (Jarvis, 1985: 51).

Within nurse education, the development of new forms of professional education such as diploma-level pre-registration programmes was associated both with new educational aims and objectives and new patterns of education. Using Rogers' definitions, it is possible to see traditional nurse education as a combination of training plus indoctrination. Modern nurse education, especially after the reforms associated with the development of diploma-level pre-registration programmes, is more student-centred learning:

> *'The intended outcome of Project 2000 programmes is to produce critical problem-solving, autonomous professionals, knowledgeable doers, who are able to respond flexibly to different situations ... The learning processes associated with the curriculum are intended to be those of the adult learner: growth through reflecting on experience ... and the development of self-direction and independent thought.'* (Miller et al. 1994: 6)

The changing philosophy of education has clearly penetrated nurse education. Phillips et al. (1996), in their review of pre-registration undergraduate programmes in nursing and midwifery, identified a range of teaching strategies:

- transmission teaching, where the teacher is the repository of 'knowledge' which is transmitted to students; assessment attends to the extent to which the student is able to reproduce that 'knowledge'
- discovery teaching, where the teacher suppresses his or her 'knowledge' in the belief that students learn best through reflecting upon experience and 'discovering' for themselves; the teacher retains a covert map of the learning to be covered and manipulates the material and symbolic environment to engineer experiences of discovery; assessment looks at the extent to which students have 'discovered' and can comprehend what they are supposed to discover
- dialogic teaching, where the teacher suppresses his or her 'expertise' and power, with the intention of identifying the learning needs of the students as defined by themselves; assessment looks at the extent to which students are able to reflect upon experience, formulate action plans in negotiation with others and implement these.

Their transmission strategy has strong elements of training and pedagogy, whereas the other two strategies are more learner-centred or andragogic. However, Phillips et al. made no comment on the relative prevalence of different forms of learning. It is clear nonetheless that some programmes have developed a curriculum based on reflection and self-directed learning (for a student view of such a programme see Holm and Stephenson, 1994).

5.3 The nursing curriculum: evidence from programme content analysis

In this section we explore the ways in which various nursing programmes are designed to enhance the competencies of their participants. We start by considering the differing stated aims of programmes, then explore the types of values they sought to develop. Finally we consider the types of knowledge and skills they sought to enhance.

5.3.1 Aims

While all the programmes studied declared their aim as developing the competencies of nurses, there was a basic division between pre- and post-registration programmes. Pre-registration programmes aimed to develop a basic all-round competence in learning disability nursing, whereas post-registration programmes aimed to enhance pre-existing competencies in specific ways.

The pre-registration programmes formed part of the overall programme of nurse education, and shared a common foundation with other branches. Thus in most documentation there were common aims for the overall programme as well as specific aims for the learning disability branch. All the pre-registration programme documentation surveyed included a statement that the aim of the programme was to educate the competent nurse who is 'fit for purpose'. For example, the overall aims of a diploma programme included the following statement:

> '*... in summary, the course team envisions the preparation of nurses who will be 'fit for purpose', having the necessary knowledge, skills, attitude and commitment to personal and professional development. These essential qualities will enable them to function confidently, flexibly, and with sensitivity to the individual needs of people with health care needs.*'
> (Pre-registration diploma programme)

In some documentation this overall aim was restated within the specific aims of the learning disability branch as follows:

- *'The intent of the Learning Disability Branch Programme is to develop a Registered Nurse who is able to demonstrate competence against the requirements of Fitness for Purpose, Fitness for Practice and Fitness for Teaching/Learning.*
- *The Learning Disability Branch Programme is designed to further the learning outcomes of the Common Foundation Programme in order to produce a competent, accountable, deployable practitioner in Learning Disabilities.*' (Pre-registration diploma programme)

Joint nursing and social work programmes aimed to educate the competent 'hybrid' practitioner:

> '*This programme aims to integrate the values, knowledge and skills to produce a "hybrid" worker who can provide a service to meet the needs of service users.*' (Joint degree programme in learning disability nursing and social work)

Most programmes and learning disability branches specified not only that the practitioner should be competent, or 'fit for purpose', but also 'reflective'. While technical skills were important, the reflective practitioner should be able to develop his or her practice through critical analysis and the appropriate use of evidence. For example, the documentation for a joint degree pre-registration programme stated that:

> '*The programme aims ... to facilitate the student's development as a reflective and competent practitioner ... [and] to enable the student to analyse, evaluate and investigate new methods and new philosophies and help shape policies for service provision.*'
> (Joint degree programme in learning disability nursing and social work)

Some programmes developed sophisticated specification of the type of nurse they were aiming to educate. For example, one aimed to facilitate:

> '*... the development of skills required to develop personally and professionally in becoming a competent, flexible, caring practitioner, teacher, and manager who is able to function autonomously and in partnership with other health care professionals, formal and informal carers and clients in the hospital and community.*'
> (Degree pre-registration programme)

Educational institutions did not want to educate nurses who were competent only when they qualified. They wanted nurses to have the capacity to develop and keep up-to-date. Thus they aimed to create a commitment to lifelong learning. One aimed to:

'Enhance the quality of the process of learning so that students are motivated to remain "fit for purpose" through lifelong learning.'
(Diploma pre-registration programme)

Similarly, but more explicitly, another aimed to produce:

'... a competent, accountable practitioner who is enquiring, flexible, innovative and proactive, a potential agent of change who thinks critically, is able to practise in a rapidly changing environment and is able to take responsibility for his or her lifelong professional development.'
(Degree pre-registration programme)

Post-registration programmes were more specialised and had aims that suited their specific role. These aimed to enhance the skills of 'competent' nurses providing them with additional competence to function as advanced practitioners or to meet the needs of specific groups of clients.

Programmes designed for advanced practice aimed to enhance not only specific nursing skills but to ensure that nurses were functioning as more sophisticated practitioners using evidence critically and reflectively. The documentation of one such programme included the following aims:

- *'To enable registered nurses to become specialist practitioners in assessing, planning, delivering and evaluating the nursing care of learning disabled people and to give support and advice to carers and significant others in the community.*
- *To develop specialist nursing practitioners, a better understanding of their role in research-based client care strategies and their potential contribution to the development of a evidence-based nursing profession.*
- *To foster a spirit of enquiry and a desire for pro-activity in further developments in the specialist practice.*
- *To afford opportunities for the development of leadership skills, decision-making skills using higher professional judgement and the exercise of professional accountability in changing environments.*
- *To promote the notion of personal and professional effectiveness through the use of evaluation and reflective skills.'*
(Post-registration specialist practitioner programme)

Specialist programmes concentrating on specific needs or groups tended to have more modest aims, focusing on enhancement of specific nursing competence. For example, documentation for a programme designed to enable learning disability nurses to cope more effectively with aggressive and violent behaviour included the following aims:

- *'To develop the knowledge, skills and attitudes that will enhance the students' ability to manage safely and effectively, clients who exhibit aggressive or violent behaviours.*
- *To develop an understanding of the moral, legal and ethical issues involved in the organisation and delivery of care for clients who exhibit aggressive or violent behaviours.'*
(Post registration nursing programme in coping with violence and aggression)

A programme designed to enhance learning disability nurses' competence in caring for clients with epilepsy included the following aims:

- *'To enable students to gain knowledge and insight into contemporary issues surrounding epilepsy.*

- *To be able to identify and manage the different forms of epilepsy.*
- *To collaborate with people with epilepsy in a positive manner to promote understanding, reduce stigmas and enhance effective clinical control and monitoring.'*

(Post-registration programme in nursing care of the individual with epilepsy)

5.3.2 Values

There was a strong emphasis, especially in pre-registration and specialist practitioner programmes, on the value base of all student learning. The documentation for a diploma pre-registration programme stated that the *'the building blocks of learning disability care are cemented in values'*. Within all programmes there was a commitment that education and practice should enhance the value and status of individuals with learning disabilities. Some placed this within the explicit framework of 'normalisation', 'ordinary living' and/or social role valorisation:

> *'The principles of normalisation, social role valorisation and ordinary living models are central themes which are revisited throughout the programme from a range of perspectives, forming a framework of philosophies which influence shared action planning, therapeutic approaches and professional values.'* (Diploma and shortened pre-registration programmes)

A programme designed to meet the future criteria of the consultant nurse as proposed by the Department of Health cited both normalisation-based models and principles and Government policy as the basis of its programme philosophy:

> *'In accordance with O'Brien's (1986) 'Five Service Accomplishments', the principles of Social Role Valorisation and the ideology underpinning the Continuing the Commitment (1996), and Sign Posts for Success (1997), the programme philosophy adopts as its central tenet the belief that individuals with learning disabilities and their families have the right to an 'ordinary life' in their local communities. In addition, the programme philosophy endorses the view that individuals with learning disabilities and their families have the right to receive effective, high quality services based upon the individual needs and to be provided within an enabling and empowering framework.'* (Post-registration specialist practitioner programme)

The main exception to this clear articulation of a value base came in specialised programmes such as those dealing with violence and aggression or forensic services. Generally these did not include clear value statements and if they did these tended to be relatively brief as in the following example from a programme offered at a special hospital, which was specified as a learning outcome rather than a value statement:

> *'**Learning outcome** – consider a sensitive and respectful approach to the individual's belief systems.'*

(Post-registration diploma programme in forensic care and management)

Value systems in pre-registration programmes were generally within an ethical framework based on the human rights of all individuals including those with learning disabilities. For example:

> *'... people with a learning disability/mental handicap have the same human value as other members of society. They have the same rights and as far as possible, the same responsibilities as other members of the community.'* (Pre-registration diploma programme)

Documentation regularly included statements that people with learning disabilities should be afforded the same dignity and respect as other members of society. For example, a specialist practitioner programme included the following statement:

'The philosophy of the Department of Nursing Studies centres around the value of the person, based on a belief that each person is unique and contributes to society in so far as their heritage, ability and health (social, mental and physical) allows.' (Post-registration specialist practitioner programme)

Within this ethical framework the role of the nurse was conceptualised as promoting the dignity of people with learning disabilities by empowering them and enabling them to make choices:

'The Course Curriculum promotes the values and practice of treating clients and all others as unique individuals, with the right, as far as they are able, to be consulted about and to participate in their own care. For the client to have the opportunity to make informed decisions and choices and be empowered, whenever possible, to overcome their own problems and difficulties is pivotal to the course.'

(Joint pre-registration diploma programme in nursing and social work)

Within some programmes addressing specialist needs and skills it was possible to identify similar concerns with empowerment, as in the following extract from a programme, which was designed:

'... to help professionals acquire the knowledge and proficiency needed to enable individuals with learning disability and challenging behaviour to have full access to their own community, develop living skills, enabling them to actively participate, and generally benefit more completely from life experiences. This module also aims to assist nurses to examine and understand responses to challenging behaviour and implications for practice.' (Post-registration programme on challenging behaviour)

Another specialised programme also included a strong value statement, but the documentation indicated that it was not unique to the programme but was the value base for all the department's nurse education:

'Society consists of individuals and groups of individuals who have the right to live in harmony, tolerating each other's beliefs and value systems. We believe in the value of education as an enabling power, and in the value of the family, however the individual defines it, seeing it as a primary source of love, intimacy and support for the individual.'

(Post-registration programme in coping with violence and aggression)

Most specialised programmes either did not include an ethical framework, or it tended to be utilitarian rather than rights-based, with an emphasis on specific benefits for service users. The following extract illustrates this approach:

'The identification of physiological, neurophysiological, psychosocial factors and subsequent understanding of the individual needs of this group of service users rest at the heart of professional intervention in order to promote a healthier lifestyle and quality of life.'

(Post-registration programme in nursing care of the individual with epilepsy)

5.3.3 Knowledge

As might be expected, programme documentation included extensive accounts of the type of knowledge students were expected to acquire. In specialised programmes, the main emphasis was on knowledge underpinning specific skills or which could be used to address a specific need. For other programmes, knowledge specification was mainly extensive rather than intensive.

The knowledge specification of such programmes tended to be limited because they were usually one- or two-module programmes, and the type of knowledge provided was treated as self-evident. Knowledge specification often formed part of the overall aims of the programme, as in the following programme for care of people with learning disabilities. This identified both care-related knowledge – for example the social dimension of care, and specialist knowledge – for example the physical, social and psychological implications of epilepsy:

- *'To appreciate the **personal implications for the individual with epilepsy and the professional involvement associated with care**.*
- *To understand the **physical, social and psychological implications** for those who suffer from epilepsy.*
- *To know how to **care holistically** for someone who suffers from epilepsy.*
- *To **understand and empathise** with the individual who has epilepsy, as well as their family, support networks and carers.*
- *To appreciate the **social dimensions of caring** for those with epilepsy as well as the need for **public education**.*
- *To understand the **relationship between epilepsy and mental illness or learning disability, and the influence of these upon the behaviour** of those who suffer from a combination of these disorders.*
- *To identify **progressive aspects of care within nursing, or multidisciplinary approaches** to caring for people with epilepsy.*
- *To identify a **professional area of nursing care** and promote a particular aspect of care in that area in relation to the knowledge and skills gained on the programme.'* (Post-registration programme in nursing care of individuals with epilepsy; emphases added)

In some specialised programmes the specification of knowledge was limited to the description of specific module content. For example, one provided the following description of the aims and content of its two modules:

> *'**Module 1:** to raise awareness of environmental, interpersonal and intrapersonal issues that cause and may also help prevent violent and aggressive incidents.'*
>
> *'**Module 2:** to develop a safe practitioner who places due emphasis on prevention of violence and who is skilled in managing.'*
>
> (Post-registration programme specialising in violence and aggression)

The pre-registration and specialist practitioner programmes provided more detailed specification of the types of knowledge they were designed to provide. In a detailed analysis of 11 pre-registration diploma programmes, we identified 165 separate areas of knowledge, which could be grouped in three main areas:

- knowledge underpinning the provision of care and support
- specialist knowledge providing insight and understanding of the situation of people with learning disabilities
- knowledge linked to the management of care (Table 5.1).

Areas of knowledge	No. of areas identified
Providing care and support	**68**
Individual care	34
Systems of care	14
Nursing	14
Ethics	6
Specialist areas of knowledge	**65**
Human anatomy and physiology	18
Learning disabilities	17
Human growth and development	15
Health	8
Supporting academic disciplines	7
Management	**32**
Legal and professional issues	15
Management processes	10
Research and information	7

Table 5.1: Areas of knowledge identified in content analysis of diploma pre-registration programmes *(n = 11)*

Given the common function of and approval mechanisms for these programmes, it is not surprising that they covered similar areas. All documents claimed the programmes provided knowledge in each of the three areas. However a more detailed breakdown of the contents indicated that in each area there were 'essential' topics included in nearly all programmes, as well as 'optional' topics which were only included in a minority. Thus in terms of providing individual care, the topics which were taught in over half the programmes included:

- the influence of social, political and cultural factors on care
- sexuality
- impact of child with learning disabilities on the family
- impact of culture on health of individuals
- caring for the person with challenging behaviour
- complementary therapies.

Some topics were surprisingly treated as optional and taught only in a minority of programmes, these included the care of the person with autism and the role of the family in providing care.

The core topics relating to systems of care included:

- social policies relating to people with learning disabilities
- the role of the multidisciplinary team
- the role of multi-agency support
- inequalities in health status and provision
- the health care system
- available services.

Again some topics were surprisingly optional including child protection services and voluntary agencies.

In the nursing area the core topics included:

- nursing models and theories, the development of nursing
- the role of the learning disability nurse
- the role of the mental health nurse.

The surprising omissions from this list were: the role of the nurse in the multidisciplinary team and the future role of learning disability nurses.

In the ethical area the core topic included ethics and ethical issues but rights were only explicitly referred to in one set of programme documentation (Table 5.2, note only the core areas of knowledge, identified in over half the programme documents are included in Tables 5.2-5.4).

Areas of knowledge	No. of programmes including topic
Individual care	
Influence of social, political and cultural factors on care	11
Sexuality	9
Impact of child with learning disabilities on the family	7
Impact of culture on health	7
Caring for the person with challenging behaviour	7
Complementary therapies	6
Caring for the person with epilepsy	6
Systems of care	
Social policies relating to people with learning disabilities	11
The role of the multidisciplinary team	8
The role of multi-agency support	8
Inequalities in health status and provision	8
The health care system	7
The services available	7
Nursing	
Nursing models and theories	10
The development of nursing	10
The role of the learning disability nurse	8
The role of the mental health nurse	6
Ethics	
Ethical issues	9
Ethics	9
Advocacy, choice and empowerment	7

Table 5.2: 'Care' topics identified in content analysis of diploma pre-registration programmes *(n = 11)*

While caring formed an important theme within the curriculum, almost equal weight in terms of number of topics was given to specialist knowledge underpinning the caring process (Table 5.3). Programmes included teaching on traditional topics such as anatomy and physiology, for example, core topics included: nutrition, the musculoskeletal system; the nervous system; the immune system; and the digestive system. However this was balanced by topics relating to human development, learning disability and health with core topics including:

- the causes, identification and social responses to learning disability
- child development
- the development of key human skills
- health promotion
- factors which adversely affect health.

The programmes also included traditional academic disciplines such as biology plus the study of social science disciplines such as psychology and sociology.

Areas of knowledge	No. of programmes including topic
Human anatomy and physiology	
Nutrition	7
Musculoskeletal system	7
Nervous system	6
The immune system	6
Digestive system	6
Learning disabilities	
Causes of learning disabilities	8
Learning disability, labelling and stigma	7
Introduction to learning disability	6
Identification of learning disabilities	6
Human growth and development	
Stages of human development	10
Children, developmental theories	7
Developmental play	7
Development of self-awareness	6
Development of reflection	6
Human health	
Health and illness	9
Health promotion	9
Factors which adversely affect health	9
Supporting academic disciplines	
Biology	10
Psychology	10
Sociology	10

Table 5.3: 'Specialist knowledge' topics identified in content analysis of diploma pre-registration programmes *(n = 11)*

The documentation also indicated that programmes addressed the legal and management skills underpinning learning disability nursing (Table 5.4). The legal context and research basis of practice were addressed with core topics including:

- legal frameworks and issues relevant to nursing
- accountability
- legal issues relating to nursing, the UKCC
- advisory documents
- the research process
- research awareness.

While programmes did include specialist management topics, there did not seem to be a consensus in this area about the topics that should be studied and we could not identify any core topic.

Areas of knowledge	No. of areas identified
Legal and professional issues	
Legal frameworks relevant to nursing	11
Accountability	10
Legal issues relating to nursing	10
UKCC, advisory documents	7
Health and safety legislation	6
Research and information	
The research process	11
Research awareness	6

Table 5.4: 'Management' topics identified in content analysis of diploma pre-registration programmes *(n = 11)*

5.3.4 Developing skills

All programmes were committed to developing participants' nursing skills. They generally specified the process, some form of practice placement, and the specific outcomes, though the actual linkage between these was poorly articulated.

5.3.5 Placements

In most programme documentation the nature and type of placement were specified, but in some cases this amounted to a list of possibilities. For example, one joint social work and nursing diploma pre-registration programme included the following list:

- observational placements
- maternity units
- care of the new-born
- mental health
- child care – hospital/special units
- adult community
- learning disabilities – community learning disabilities team

- child community
- older people
- adult – hospital/residential
- social work placement of 75 days
- specialist team e.g., challenging behaviour – 15 days
- learning disability placement – 90 days – field/community or residential or specialist team (NHS/social services/private/voluntary services).

A similar programme provided more detail but did not include the desired and expected specific learning or skills outcomes. The documentation specified that students would have three of the following six placements:

- aspects of children's nursing – child assessment unit/children's ward/hospital adolescent
- promotion of health in the community – health centre/community nurses
- care of the elderly – wards/community/day hospitals/day centres/residential/nursing homes/voluntary service agencies
- maternity care of mother and newborn – wards/community
- learning disabilities – with families/formal/informal carers
- introduction to adult nursing – medical/surgical care settings.

A specialist post-registration programme in forensic care also included practice placements; while the options were specified the desired outcome was not:

- two practice placements – four weeks each
- diverse settings – special hospitals, prisons, regional secure units, NHS facilities, probation services, community initiatives
- can work for own organisation but not on own unit/ward.

Only a minority of programmes linked the description of practice placements with learning and skills outcomes as seen in the following extract:

> *'The placements ... provide a range of learning and experiential opportunities. The placements are intended to give the nurse a broad experience of people and their carers who are affected in some way by epilepsy.*
>
> *The placement areas were selected in order to facilitate the nurse's learning both in theory and practice.*
>
> *[The placements take] place on:*
>
> - *the medical unit (13-bedded unit)*
> - *the adult assessment unit (18-bedded unit)*
> - *the children's epilepsy unit (homely environment)*
> - *the challenging behaviour unit (24 beds)*
> - *the clinical unit (day unit, 9-5).*
>
> *All of the above are within the [specialist centre for people with epilepsy].'*
> (Post-registration programme in nursing care of the individual with epilepsy)

A pre-registration programme also linked the description of the placements with learning and skills outcomes:

'The university is committed to providing every student with a placement which meets their learning needs in an educative and supportive environment under the supervision of an accredited clinical supervisor/ practice teacher.

- *Year one – Placements with the primary health care team, and an acute health care experience.*
- *Summer placement one – Student undertakes placement with people who have multiple disabilities in residential or home care setting.*
- *Year two – social work placement – placement in local social services agency.*
- *Summer placement two – with a family who has a child with learning disabilities.*
- *Year three – final integrated placement in learning disabilities in either health or social service setting.*

Aims of learning disabilities placements are to enable the student to:

- *gain experience of working in a range of health care settings meeting a broad range of client needs in order to facilitate the transfer and consolidation of their learning*
- *demonstrate a developing competence progressing from a generic understanding to a more precise and specialist focus in relation to their practice*
- *achieve the desired learning outcomes and demonstrate the competencies as required by UKCC, ENB and CCETSW.'*

(Joint social work and nursing pre-registration programme)

The documentation provided specifications of the skills that students were expected to have on successful completion of the programme. To identify how programme designers defined the requisite skills of registered nurses we undertook a detailed analysis of the same 11 pre-registration diploma programmes that provided the evidence for the knowledge base. The required skills could be grouped into four main areas: care skills required to provide care and support for clients, management skills, research skills and personal skills (Table 5.5). There were fewer skills identified than areas of knowledge (94 skills vs. 165 areas of knowledge), but since there was greater consensus about necessary, or core, skills there were a similar number of core skills and areas of knowledge (40 skills vs. 47 areas of knowledge). The widest range of specification in the documentation was for care skills, and the narrowest for personal skills. We noted in our discussion of areas of knowledge that management knowledge was included but it did not feature prominently, as there was no agreement between programmes on core management knowledge. In the skills area, the situation was different. There was agreement over 12 core management skills which students were expected to acquire. As we observed in our study of nurse education in relation to risk and decision-making, such competencies are seen very much in terms of practical skills to be acquired in practice placement, and not in terms of underpinning knowledge taught in class (Alaszewski et al., 2000).

Skill	No. of areas identified	(core skills)
Care	39	(10)
Management	27	(12)
Research and information	16	(10)
Personal	12	(8)

Table 5.5: Main skill area identified in content analysis of diploma pre-registration programmes *(n = 11)*

The care skills included skills common to several branches of nursing; for example, general nursing would include care planning, lifting and handling, observation and drug management and administration as core skills. Counselling, managing aggression and challenging behaviour and family-centred care were also used by mental health nurses (Table 5.6; note in Tables 5.6-5.9 we only present core skills, those that are evident in over half of the programmes).

Care skill	No. of programmes
Care assessment, planning, implementation and evaluation	11
Counselling	9
Lifting and handling	7
Observation	7
Drug management and administration	6
Maternal care	6
Management of aggression and conflict	6
Managing challenging behaviour	6
Family-centred care	6
Providing opportunities for work and leisure	6

Table 5.6: Core care skills identified in content analysis of diploma pre-registration programmes *(n = 11)*

The specification of management skills reflected the distinctive skill profile of learning disability nursing. While branches of nursing might include topics such as record-keeping, clinical audit, quality enhancement, time management and leadership, the prominence given to multidisciplinary and multi-agency working and change, decision-making and risk, reflect the distinctive complex and changing working environment of learning disability nurses.

Management skill	No. of programmes
Working as part of MDT	11
Resources management	9
Managing/initiating change	8
Multi-agency working	8
Decision-making	7
Record keeping	7
Risk assessment and management	7
Critical thinking/analysis	6
Resourcing, purchasing, providing and contracting	6
Clinical audit and quality enhancement	6
Time management	6
Leadership	6

Table 5.7: Core management skills identified in content analysis of diploma pre-registration programmes *(n = 11)*

The core research skills identified in the programme documentation reflected the higher education environment and influence on nurse education, together with the overall commitment to developing research and evidence practice within nursing. All nurses completing higher education-based programmes would be now be expected to acquire these core skills.

Research skill	No. of programmes
Computer skills	10
Study skills	9
Doing research	9
Research/evidence-based practice	7
Academic style and referencing	7
Presentation skills	7
Library skills	7
Data collection	6
Literature research and review	6
Portfolio construction	6

Table 5.8: Core research skills identified in content analysis of diploma pre-registration programmes *(n = 11)*

While most of the core personal skills reflect the commitment within current nurse education to educate the reflective practitioner who is committed to lifelong learning, the emphasis on communication and interpersonal skills reflects the importance within learning disability nursing of these specific personal skills.

Personal skill	No. of programmes
Communication skills	11
Reflection/reflective practice	10
Self-awareness	9
Self-directed learning	8
Interpersonal skills/relationship building	8
Teaching, supervising, assessing and mentorship	6
Lifelong learning	6
Special communication techniques	6

Table 5.9: Core personal skills identified in content analysis of diploma pre-registration programmes *(n = 11)*

5.3.6 Comment

Our review of the programme documentation of Board-approved programmes for learning disability nursing indicated that all pledged to develop competent practitioners who were committed to the interests of people with learning disabilities and had the appropriate knowledge to provide care that enhances the autonomy of those people. Next we consider the views of current programme leaders who had to implement this curriculum.

5.4 Delivering the curriculum: the lecturers' perspective

We interviewed lecturers in charge of eight learning disability programmes to examine their perceptions of the aims of their programme and how they saw their programme contributing to learning disability nurses' competence. Within the context of interviews, the lecturers could not provide the same level of detail as was included in the programme documents and therefore tended to highlight key issues and themes.

5.4.1 Aims

All lecturers said that the main aim was to create or enhance competence, but they varied in how they defined competence. One lecturer responsible for a pre-registration degree accepted he had an idiosyncratic approach, emphasising the underpinning value-base of nursing, but saw this as having to adjust to the changing policy context:

> *'I think it depends on where you're coming from. My perspective, I'm very much into social models, this sort of thing. Value based philosophies of nursing and that is where the majority of my teaching comes from ... I, as you know, run the degree programme and I think, on reflection, my bias in terms of this social value, philosophical basis of nursing comes through there. So I think that is shown there. We are beginning to redress that because of the changes of more dominant push towards health care for learning disabled people and trying to refocus on that position but that is taking time because obviously I'm requiring colleagues to take a bit more of an input into that.'* (Pre-registration degree programme)

In contrast, a lecturer responsible for a post-registration programme on people with learning disabilities and mental health problems saw its aims in terms of technical competence, the knowledge and skills required to identify and treat mental health needs in people with learning disabilities:

Interviewer: *'What do you see are the main aims and objectives of the course?'*

Lecturer: *'It is to provide people with current knowledge i.e., current published literature in the field of dual diagnosis. So that's one of the planned objectives, because people often say they don't know much about what is published and I keep telling them this – quite a large amount is published ... I think another objective is to provide help in terms of reporting symptoms etc. etc. for an effective detection of a mental health disorder and helping other professionals. Helping the psychiatrist to make a diagnosis. Because that is very important in terms of third party reports ... The third and the main objective is to explore the kind of relationship with challenging behaviour and mental health disorders and to sort of look at the therapeutic interventions based on needs and needs assessment, cognitive behaviour.'* (Post-registration programme on people with learning disabilities and mental health problems)

The other lecturers tended not to define competence in requisite values, knowledge or skills but conceptualised it more in terms of fitness for purpose or practice. This was defined in a number of ways. Several lecturers saw it in terms of flexibility. For example, a lecturer responsible for a joint nursing social work degree programme saw competence in terms of ability to work in either health or social care:

'It equips practitioners to work across all fields and with the partnerships and action documents in the current health bill that will become a new Health Act then they, these people will be the practitioners for the future. If we're talking about health and social services working closely with each other on things like budgets and big commissioning then people that qualify with a dual qualification are going to be key and influential people for new services.' (Pre-registration degree programme in nursing and social work)

While a lecturer responsible for a diploma pre-registration programme felt the programme aimed for balance:

'We try to produce at the end of it a balanced practitioner who has a wide range of skills that is able to work in a wide variety of settings. So we try to avoid pushing them down any particular avenue. The kinds of things that we've got at the back of our minds, I suppose, when we're teaching are about local requirements. But I mean that is very broad – we've got anything from a forensic unit right through to residential – so we try to avoid pushing them down a particular road.' (Pre-registration diploma programme)

Lecturers were conscious of the changing policy environment. Some saw this as an increasing emphasis on health care and health promotion. For example, a lecturer responsible for a diploma pre-registration programme commented, *'it [policy] seems to be – if I'm picking up the vibes right – moving away as well from not just social issues but it's moving back towards health issues'*. A lecturer responsible for a post-registration specialist practitioner programme saw the main aim of the programme as keeping such practitioners abreast of current policy developments:

'There is a very strong emphasis on the person-centred nature of provision, or that should be the nature of provision. It should be person-centred, it should be needs-led. There is an emphasis on equity, on equitable provision of service so, in most aspects there is always consideration of service provision to non-English cultures, for instance. We've also had a strong emphasis, since the programme started, on changes in policy, Government policy, social policy and changes in the structure of the Health Service because unless the students keep up to date with that then

it's very, very difficult for them to then go out and practice in reality. So those, those are fairly strong elements.'
(Post-registration specialist practitioner programme)

In some programmes, there was a strong emphasis on meeting employers' requirements. For example, a lecturer on a community learning disability programme that depended on funding from local trusts commented that:

'They are being trained to be residential or community nurses depending on what the trust requires. We have one trust that takes one student per year, and they provide children services only, whereas another trust provides adult services only. The focus for them will be working with children as opposed to working with adults.'
(Post-registration programme in community learning disability nursing)

Other lecturers acknowledged the importance of employers' expectations but sought to balance them with other broader aspects of competence:

'Yes, you'll find that sometimes it's a mix match of expectations in relation to what the managers want and what they expect, and sometimes they want an all singing, all dancing, fully armed, fully equipped practitioner after three years and that's totally unrealistic. What we try to do is help the students work through developing a whole series of frameworks and ideas that they are then able to apply those across the contexts, so if it problem solving they can use their nursing process and this, that and the other.' (Pre-registration diploma programme)

5.4.2 Knowledge

We asked lecturers about education in the educational institution, especially what they expected students to learn from classroom-based teaching. Some responded by identifying key areas of knowledge. For example, the lecturer responsible for the post-registration programme on dual diagnosis emphasised the importance of providing student with the 'latest' knowledge in this area:

'We try and provide up-to-date knowledge in relation to dual diagnosis and I think that is very much a strength ... We provide the cutting edge of research such as needs assessment and dual diagnosis ... We're at the cutting edge ... There is the kind of various professionals involved in this course. Like the psychiatrist actually talks about assessment and diagnosis and detection ... and then the cognitive behaviour therapy – I think that's quite a useful thing that's actually covered and well received by people. So it's the broad various professionals plus the knowledge base and the cutting edge of research and some of the real practice and how we can put this into practice.' (Post-registration programme on dual diagnosis)

A lecturer responsible for a pre-registration programme indicated that the knowledge was context-specific and changing according to the issue or user group being examined, commenting that: .

'It depends upon, I mean where the students are at the moment, they've gone to work with a group we call working with people with major care needs, so that's multiple disabilities and so-called challenging behaviour and so the theory input from outsiders will be pitched around those areas, we do have some input from the regional forensic service and we've just got someone in our team who is a senior nurse, behavioural therapist so he will supplement in that way, there's quite a variety.'
(Pre-registration programme)

However, many responses were evasive. Lecturers avoided specifying or cataloguing areas of knowledge, as they saw teaching as primarily a means to an end. As one stated: *'I think we're trying to prepare them to work in a wide variety of settings'* (Shortened pre-registration programme). Another lecturer specified areas of knowledge but indicated that this specification depended on the needs of specific employers:

> *'I would say the primary focus is on health or promotion or surveillance and I think that's tended to be lost in learning disabilities generally. There's been a big emphasis on social care, quite rightly, but … our trusts they want us to spend more time focusing on health, physical care in particular, conditions such as epilepsy, diabetes, they want our students to know about social care but when it comes to paying the wages, they seem to suggest that they'd be willing to pay wages for a health carer to do health.'* (Post-registration programme in community learning disability nursing)

Most lecturers saw classroom-based teaching as a preparation for practice, and some gave primacy to employers' definitions of practice needs. One saw the main function of class teaching as preparing students for the 'world of practice':

> **Lecturer:** *'What we're trying to do is enable them to work in a variety of settings. It gets quite difficult sometimes because the students sometimes have their own agenda about wanting to work in particular areas and it's a fine balance and I think we've been fairly successful at it in that we have responsibilities in terms of the programme preparing for somebody who can work in a variety of settings but also allowing the students to develop their own special interests. So, we try and balance the two so that at the end of the day the student gets a valuable experience but also that the people who pay the money – they're getting what they want out of the programme.'*
>
> **Interviewer:** *'The employers seem quite important …'*
>
> **Lecturer:** *'Yeah, yeah. The feedback that we get back from the employers is really important. They sit in on programme committees and we have formal links in terms of link teachers who find out whether they're happy with the students that they get. On the whole I would say that the feedback we get from when they do their round of interviews is that it's OK. You know, there's been one or two problems but it's more been about interview technique rather than about the knowledge that they have.'*
>
> (Diploma pre-registration programme)

5.4.3 Skills

Lecturers seemed more comfortable discussing the skills that they expected students to acquire than the purpose of classroom-based teaching. Most programmes had practice placements and these were the key location for skills acquisition. However, even in specialist programmes that were entirely college-based, the lecturers clearly expected students to use the knowledge they had gained to develop skills. For example, one lecturer commented that:

> *'Yes, some people … I've seen in [local area] quite a few people are actually using the rating scales for screening instruments which is actually an improvement. At least they've actually taken something away from here. I think people adapt … what they actually learn from here into their practice and how effective it has been obviously I haven't made any follow up studies of any nature.'*
>
> (Post-registration programme in learning disability and mental health)

Another programme for specialist practitioners did not routinely provide placements but expected the students to develop a more sophisticated understanding of their practice:

> *'With the degree course it's not so much a case of preparing them because on the programme they've already had two years' post-registered experience. What we ask them to do is reflect on their current practice, critically analyse their current practice and develop their skills based on the ENB 10 key characteristics, in practice elements.*
> (Post-registration specialist practitioner programme)

While lecturers tended to see classroom-based teaching as a means to an end, they saw practice as the key aspect of learning and were generally able to provide a detailed list of the skills that they expected students to acquire. For example, one lecturer identified a range of mainly caring skills:

> *'Well some of the major ones that come to mind are obviously areas such as assessment – using tools of assessment and understanding the process of assessment. Understanding how to use those assessments with our client group. So assessment is one major part across a whole gambit of different needs for people with learning disability. There's obviously a heavy commitment in respect to communication skills. The issues, again, of value-base, empowerment, advocacy, communicating with clients about that value in terms of developing services and meeting needs. Ensuring that people with learning disabilities are able to play a part in that so their own individual skills as communicators with a learning disabled person, at the interpersonal level and at the more wider level with other groups in terms of their day-to-day activities and skills is a major part of the programme. I mean, obviously you could say more about advocacy issues, empowering and enabling issues but also they have to be aware of various specific more practical skill-based activities. For instance, various health interventions, caring for people who also have medication regimes, for want of a better term. The processes of doing that, the understanding and the theory behind that, for example, but also things such as being aware of other health issues. People with diabetes come into the curriculum fairly positive recently, dementia, obviously dual diagnosis, mental health problems. So looking again at increasing those issues about more specific mental health needs in the actual practical activities that a nurse will have to do – monitoring people's epilepsy, for instance.'*
> (Diploma pre-registration programme)

Lecturers varied in the ways in which they specified core skills. On one joint nursing social work programme, lecturers were so keen to stress that students were competent in nursing as well social work that they emphasised traditional physical care skills:

> *'They will have had and do have all the traditional nursing skills including tube feeding and care of gastrostomies, care of tracheotomies etc. as more people with very severe learning disabilities are actually supported in their home environment and it's important that the learning disability nurses actually have the skills to support the individuals and all their carers doing that.'* (Joint pre-registration degree programme in nursing social work)

Lecturers emphasised the importance of students developing care skills in their placements. In some cases students were given responsibi for a caseload:

> **Interviewer:** *'So in terms of practice, what skills do you prepare the student with?'*

Lecturer: *'Right, again a wide variety. We use a client attachment. So it's working with a caseload, prioritising the care, time management, case management, the IPP so everything that's involved with that as well. So they take on like a mini caseload. What's the question again?'*

Interviewer: *'What skills do you prepare the student with in terms of practice?'*

Lecturer: *'Yes, yes. It is mostly around that – care management, case management. We're really preparing them for that, yes.'*
(Pre-registration diploma programme)

Lecturers also expected students to develop management skills, especially in the final placements on pre-registration programmes. Lecturers on a joint nursing social work degree programme described their expectations in the following way:

Interviewer: *'What about management skills then?'*

Lecturer A: *'During this current placement this is an ultimate placement they are all expected to do things such as completing duty rotas, and taking the lead role and running ship if you like or being the person in charge, being there to support [other staff] doing that.'*

Lecturer B: *'And also it's the assessment pack for whilst they're on placement, a lot of the core competencies they are expected to achieve are about supervision of other, not just clients or residents, but supervising other members of staff. And also in terms of management in practice there are other core competencies around cost effectiveness of services and efficiency of services.'*

Interviewer: *'Resources, so they could manage a budget?'*

Lecturer A: *'Yes.'*

Lecturer B: *'Yes. We have some understanding about managing budgets.'*

Interviewer: *'So you might find a student being able then to run a small unit then very quickly in their job.'*

Lecturer A: *'Yes. Well, one of the graduates went straight to being a care manager and that involves managing budgets.'*
(Joint pre-registration degree programme in nursing and social work)

5.4.4 Comment

Lecturers' descriptions of their programmes matched the descriptions provided within the programme documents. They saw the main aim of their education programmes as developing and enhancing the competence of learning disability nurses so that they were fit for practice. They saw competence primarily in terms of the development practical skills for providing care and managing services and some lecturers emphasised the importance of meeting employers' requirements. Only exceptionally, for example in a specialist programme on dual diagnosis, was there a clear and separate recognition of the importance of the knowledge underpinning the development of competence. We now consider whether the prime consumers of this education, the students, view their education programmes in the same way.

5.5 Students' views of education

In this section we consider students' perception of their education, drawing on our focus group interviews with 57 final-year students on eight programmes.

5.5.1 Aims and objectives of the programmes

The students were asked to identify what they thought were the aims and objectives of their programmes. Although one honestly admitted that she had *'no idea'* (6/1), most made some attempt to identify them. A number found difficulties in identifying the overall aims and objectives since many pointed out that they had been given specific aims and objectives for individual modules but no aims and objectives for the programme as a whole. As one pointed out: *'I don't think they've really given us clear aims for the end of this programme'* (2/3). Only one student felt truly confident about identifying the aims and objectives of her programme: *'I've found it basic, really. You come out with a degree.'* (8/4). The majority of students did not share this rather cynical view and tended to see the aim of their programme in terms of obtaining a nursing qualification. For example, one identified the main programme aim was to *'produce a qualified practitioner, I think.'* (5)

Most students accepted that the prime aim of their programme was to provide them with the necessary skills to be a learning disability nurse. One identified the main programme aim as *'preparing us to perform the role of a learning disabilities nurse'* (6/3), whilst another commented that: *'I think they're just looking for us to be able to fulfil the role of the learning disability nurse effectively'* (2/3).

The joint learning disability nursing and social work students appeared more confident when discussing the aims and objectives of their programmes. One felt that the aim of her programme was to produce:

> *'... a worker that's able to work with people with learning disabilities to have a holistic knowledge of social care and health care to provide a good service.'* (5)

Another joint student gave a similar answer:

> *'I think they're trying to give us a very basic understanding of the social work and nursing and so that when we go out into the placements we are able to use that.'* (4/1)

The same student and her fellow students went on to discuss how they considered that the aims and objectives of their programme also included:

> **Student A:** *'To give us the underlying values of social work and from nursing I think it is to give us the skills.'* (4/1)
>
> **Student B:** *'I think it's more to like bridge the gap between nursing and social work and to like, merge the commonalties between the two.'* (4/3)
>
> **Student C:** *'Our training has to be to fulfil both roles at once rather than separately training us to do nursing or social work. They're training us to do both.'* (4/4)

There was agreement that the main aims of post-registration programmes were to develop or enhance students' skills so that they could be more effective practitioners. A post-registration student articulated this in the following way: *'the thing they tell you is it turns you into a specialist practitioner. That's got to be one of them [aims]'* (8/3). Another post- registration student emphasised the importance of reflection: *'A reflective practitioner. Not just, sort of, doing things'* (8/2).

A student on a pre-registration diploma emphasised management and leadership:

> *'They've mentioned about leadership and management. You know – preparing us for, that's the role that we're going to be fulfilling.'* (2/4)

An RGN undertaking a shortened learning disability nursing programme emphasised the way her programme was designed to develop her existing skills so that she could undertake a new role:

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'They've tried to prepare me to really use my nurse education that I've had previously into a different client group.' (7/1)

5.5.2 Nurse education: a positive choice

Whereas most students in the focus groups recognised the explicit value-base of their programme and especially the importance of normalisation and ordinary living approaches, their own values were made explicit in discussions about how and why they chose the programme.

Most saw their decision to train as a learning disability nurse as a positive choice. A number reported that before they decided to do nurse training, they had worked with people with learning disabilities and as a result decided to pursue a nursing qualification in this area. As one stated:

> *'Before starting this course I used to work with people with learning disabilities. I enjoyed it so that's why I wanted to have the qualification.'* (2/1)

Another said that working with people with learning disabilities was *'a passion. That was why I went into it'* (7/1).

Several students indicated that they had chosen learning disability nursing in preference to any other branch of nursing. One student on a pre-registration programme indicated that she had chosen learning disability nursing because of its holistic focus: *'it's the one that looks for all care – not just a person's health but for everything'* (6/2). Several students indicated that they wanted to train so that they could improve the position of people with learning disabilities. One spoke of the *'neglect, sometimes abuse'* (2/4) of people with learning disabilities that she had witnessed through previous care work. She had decided to qualify as a learning disability nurse so that she:

> *'... could be in a position of management knowing what I was doing first of all, before I could confront anything else. But also so I could try and change things.'* (2/4)

Another student also demonstrated how she wanted to use knowledge gained from her programme so that she could go back into practice and improve services.

5.5.3 The use of education

Students on post-registration programmes perceived such educational opportunities as a way to develop and enhance their existing knowledge and skills. As one pointed out the programme would: *'raise my awareness and [teach me] more diagnostic skills'* (9/6). Students also seemed to feel that they were not only enhancing their own knowledge and skills but that they could share these with colleagues when back in practice; they would take away the information and *'share with [their] colleagues'* (9/6). They said that upon their return to the practice area they would be expected to disseminate the knowledge they had gained with their colleagues resulting in, as one said: *'a knock-on effect, a ripple effect'* (9/6).

A pre-registration student commented that she was undertaking the programme partly because of the personal satisfaction it gave her. She stated that: *'being qualified as a nurse is an achievement for me'* (3).

The post-registration specialist practitioner students, however, did not consider that a nursing qualification was sufficient to give them the power to make changes. They argued that: *'nobody would listen to you'* (8/1) if they did not have the status that a degree would confer. They believed that a degree would make people more likely to take notice of them. As one pointed out, with a degree: *'you sound as though you know what you are talking about though, don't you? Even if you don't, you sound as though you do'* (8/2). Several of the same nurses who were undertaking a specialist practitioner degree admitted that they were doing the programme

because they *'wanted a degree basically'* (8/2) rather than having any desire to study learning disabilities in more depth. As one reported: *'I wanted a degree and I was going to get it regardless. I didn't want to be the only one in my family without that bit of paper'* (8/3).

For many students, nurse education was a way of improving their status, while at the same time ideally helping people with learning disabilities. Indeed they saw these two factors as linked – by developing knowledge and skills they could use their position to help people with learning disabilities. One had decided to qualify as a learning disability nurse so that she: *'could be in a position of management knowing what I was doing first of all, before I could confront anything else. But also so I could try and change things'* (2/4).

5.5.4 Theoretical and practical elements of the programmes

In the focus groups we used trigger questions to explore students' experience of the theoretical and practical elements of their programmes. Generally they identified lectures as the principal source of theory, and that their primary function was to point the students *'in the right direction'* (2/4) of study and further knowledge. The general consensus emerged that: *'lecturers give you the tools to work with'* (1/m) leaving it up to the students to: *'go out there and read'* (8/3). The students all agreed on this and that: *'if you've got to listen to someone and take notes and go away and do little exercises you learn a lot more'* (3/2).

Lectures were also seen as preparing students with specific skills. One group felt that their lecturers tried to instil in them the ability to work as: *'research-based practitioners'* (8/2) whilst another felt they learned how: *'to think independently and evaluate things and stand back and look at whole picture'* (1/f). They added that the lectures taught them how to: *'question things'* (1/m) such as: *'rights, responsibilities, you know, values'* (1/m) which they did not have the confidence to do previously.

Students felt that practice placements offered more learning opportunities than classroom-based teaching and enabled them to: *'build upon the theories we've had in class'* (4/2) and also: *'to apply the theory'* (4/1) they learned in the classroom. Additionally, they perceived practice placements as a way of putting *'the theory into practice'* (6/2). Students felt that they could develop their skills and confidence as placements were intended to build *'your confidence a bit'* (3).

With the exception of the adult nurse undertaking a shortened learning disability nursing programme, most pre-registration students reported similar placement experiences. The general nurse felt that her experience of placements differed from those of the other students on the branch programme she had joined because:

> *'... on placement I have been treated as a qualified nurse and when I describe my placements to the others there's no bearing, there's no similarity at all.'* (7)

5.6 Summary and comment

Traditional nurse education was designed to produce nurses with the same practical skills; contemporary nurse education is more flexible. It is designed to provide students with learning opportunities so that they can develop appropriate skills grounded in theory and evidence. Central to this process is the creative interaction between classroom-based teaching and practice experience.

The learning disability programmes surveyed drew on contemporary thinking about nurse education. They aimed to produce flexible nurses who were not only fit for current practice but had the ability to adjust to changing situation through lifelong learning. The curriculum was grounded within a strong commitment to the needs and interests of people with learning disabilities and practice that empowered them. The programmes clearly specified appropriate knowledge including that underpinning care skills, specialist underpinning theory

and knowledge of management. The programmes also specified necessary skills including care skills, personal skills and research skills.

Our interviews with lecturers and students were consistent with the evidence from programme content analysis, though given the format of an interview lecturers and students could not discuss the programme in the same level of detail. They only highlighted key features. There was agreement that the learning in placements was crucial for the development of competence in nursing and that the acquisition of knowledge was very much a means towards an end, a prerequisite for developing skills in and through practice.

DEVELOPING SKILLS: PERCEPTIONS OF THE LEARNING PROCESS

6.1 Introduction

In this chapter we explore perceptions of the learning process, especially the development of appropriate skills. We start with the primary consumers of education, current and past students, we then consider the perceptions of 'secondary consumers' who need the services of the primary consumers, employers, users and families. We start with a short commentary on the learning process. As noted in Chapter 5, it is generally accepted that the main purpose of nurse education is to educate nurses who are fit for practice. In this section we consider how nurses are expected to acquire the requisite skills.

6.2 Learning to practise

The nursing curriculum outlines the key values, knowledge and skills that nurses are expected to acquire on completing a specific programme. The extent to which they develop skills and are ready for specific aspects of practice form the focus of this chapter. To set the context we start by considering the nature of the learning process.

6.2.1 Using knowledge to develop skills

Debates in the 1970s and 1980s resulted in a rethinking and reconstruction of nurse education. Although some traditionalists argued that it should concentrate on the development of practical 'common sense' skills and that the development of a theoretical knowledge-base was damaging (see Allen, 1997: 190), this did not command extensive support (Melia, 1987; Campion, 1992). There was strong commitment to the view that nurses should be prepared for the practical aspects of clinical practice (Bines and Watson, 1992), and that theory should form the basis of the development of clinical skills. As Benner (1984: 11) noted:

> *'Clinical expertise has not been adequately described ... in nursing ... adequate description of practical knowledge is essential to the development and extension of nursing theory.'*

As part of this debate, the Board designed a new syllabus for 'mental handicap' nursing that was seen by many as exemplary, identifying the skills and therefore the role of the learning disability nurse (ENB, 1982). By the 1990s most commentators saw clinical practice as a crucial component of nurse education and the main location for the development of professional competence:

> *'Knowledge, skills and value commitment are the outcome of clinical practice experience.'* (Reilly and Oermann, 1992: 49)

However at the same time there was growing concern about whether students were able to exploit the learning opportunities provided by clinical practice to develop appropriate skills. For example, Nicol and Glen (1999: xi) noted that: *'newly qualified nurses often lack competence in what are frequently basic fundamental skills'*. Carlisle et al., exploring and describing the changing role of the nurse teacher between 1991 and 1994 following the introduction of Project 2000, pointed out:

> *'There was a consensus on the belief that pre-registration students needed help to apply theory to practice and cannot just be left to draw links for themselves.'* (Carlisle et al., 1997: 391)

A similar point was made by Nicol and Glen (1999: xi):

'It is no longer sufficient to rely on students acquiring clinical skills by unstructured exposure in placement. Skills teaching must be planned into the curriculum.'

Glen (1999: 10) further argued that:

'Skills teaching must be structured and designed to prepare students for their placement experience so that they can optimise their learning within the context of increasingly scarce and finite resources.'

There has been increasing recognition in nurse education that teaching of theory and learning of skills need to be integrated:

'Teaching and learning, two discrete processes, are interrelated so as to form a gestalt that reflects a dynamic process.' (Reilly and Oermann, 1992: 45)

As Phillips et al. (1994) pointed out, the acquisition of competence is a complex process. Their study examined competence in the context of assessment within nurse education and practice. They noted that while a statutory definition of competence has been in place since the Nurses, Midwives and Health Visitors Act 1983, it is a narrow definition based on minimum standards. They were concerned that nurse education may be based on this minimum and therefore be missing developmental opportunities. Instead they argue that competence should be:

'An expression of work where work itself includes the whole complex of processes through which individuals learn, judge, make decisions and act to manipulate and transform the world for human purposes, then critically reflect on the results and begin again the process of work.'
(Phillips et al. 1994: 79)

Thus, competence is itself an educational process requiring reflection, learning and development.

6.2.2 Using teaching strategies to overcome the theory-practice gap

Overcoming this theory-practice divide involved the development of a link between theory and practice by encouraging certain teaching and learning strategies, in particular a process of reflection, both when decisions were being made (reflection-in-action) and afterwards (reflection-on-action) (Schön, 1991). The student was to be treated as an active participant in the teaching process and encouraged and provided with opportunities to explore the relationship between theory and practice.

This developing interest in reflection may be attributed to concerns about the theory-practice gap. Clark (1986) suggested that reflection is the cornerstone to uniting theory and practice in nursing, whilst Bines and Watson (1992) believe that practice is central to nurse education. However, simply to be practising is not enough, because being present in the clinical area does not necessarily mean that learning takes place (Atkins and Murphy, 1992). Burnard (1988) considered that it is only by reflecting and giving meaning to this personal subjective experience that knowledge occurs. In other words, reflection acts as the link between experience and learning from that experience (Platzer et al., 1997).

Within this approach there was recognition of three components:

- formal teaching, especially of underpinning theory
- clinical placement for the development of practice skills
- the structuring of individual and personal experience through the process of reflection.

This approach places the students' experience of practice at the centre of the educational process. Schön's work has been frequently taken as a starting point in the discussion of reflection:

'In real-world practice, problems do not present themselves to the practitioner as givens. They must be constructed from the materials of problematic situations which are puzzling, troubling, and uncertain. In order to convert a problematic situation to a problem, a practitioner must do a certain kind of work. He must make sense of an uncertain situation that initially makes no sense. When professionals consider what road to build, for example, they deal usually with a complex and ill-defined situation in which geographic, topological, financial, economic, and political issues are all mixed up together. Once they have somehow decided what road to build and go on to consider how best to build it, they may have a problem they can solve by the application of available techniques; but when the road they have built leads unexpectedly to the destruction of a neighbourhood, they may find themselves again in a situation of uncertainty.' (Schön, 1988: 66-67)

Professionals need to learn to manage such uncertainties by experimenting in controlled conditions, where the consequences of error can be minimised. Murphy and Atkins argued that the practical placement should be organised to provide controlled and safe conditions for student learning:

'The practicum should offer conditions of safety to the learner which enables him or her to explored [sic] dilemmas and to become aware of the defences which may inhibit their growth or that of others.'
(Murphy and Atkins, 1994: 13)

6.3 Primary consumers: current students and nurses

The primary consumers of nurse education are past students who are using the knowledge and skills that they acquired and current students who intend to do so in the future. We will first consider past students drawing on our survey of current nurses and then current students using material from our focus group interviews.

6.3.1 Current nurses, former students

In our questionnaire survey we asked respondents to evaluate both their own educational preparation and that of current students. Generally they were critical both of their own educational preparation and that of current nurses.

6.3.1.1 Evaluation of own educational preparation

Respondents emphasised the managerial dimension of their first job, either in terms managing the delivery of care (92%) or managing and leading staff (61%). One nurse noted that:

'Good management skills are now far more important than they used to be for nurses. This doesn't seem to be acknowledged by the training bodies.' (0005/850)

Respondents also acknowledged the therapeutic dimension of their first job, including the use of therapeutic skills (40%) and teaching parents, carers or staff (35%). For example, one nurse stated that:

'[The] nurse has a duty and obligation to update a wide range of clinical skills, in addition to ensuring that he or she is also fully conversant with any current development in practice or change in legislation.' (0556/879)

Another stressed the need to update care skills to improve user care:

'Nursing is a process where we learn new skills daily. It is interesting to apply research-based skills to improve the care of patients.' (0208/1818)

Less than 24% of respondents felt that their education had fully prepared them for their first post, and less than 11% felt that it had fully prepared them for their current role. The majority (91%) identified one or more educational deficits that had become apparent within two years of qualification. Some did not feel that their professional education provided them with adequate therapeutic skills (see Table 6.1). For example, a nurse who had trained in the early 1990s commented on its general inadequacy: *'I found the training very much theory based, which I enjoyed, but felt inadequate when commencing practical placements'* (0675/123). Another commented: *'I found the RNMH course a poor preparation for community work'* (0005/850). A nurse who specialised in worker with older people with learning disabilities commented on the limitation of her knowledge and education:

> *'I currently work with elderly people with learning disabilities and additional mental health problems such as dementia. At the present time there does not appear to be any formal recognition of this field of nursing by the ENB or other professional bodies, and much of the literature in the learning disability journals focus on the more able, challenging behaviour or multiple handicaps. During the time I have worked with an elderly client group [approximately nine years], I have had to adapt literature etc. to my personal needs and the needs of my client group.'* (0197/400)

Respondents (Table 6.1) were particularly concerned about the lack of preparation for the managerial aspects of their first job. Indeed one felt that poor preparation for this aspect of her work had contributed to personal isolation:

> *'Continue to feel isolated. Due to poor time management/communication skills, have to learn from own experiences, not shared or very rarely.'* (0088/1821)

	Percentage of respondents
Administration and management	
• leadership/management skills	60.6 %
• how to deal with stress	38.3 %
• time management/organisational skills	22.5 %
• knowledge of legislation	0.4 %
• legal/ethical issues	0.3 %
• evaluating and developing the service	0.1 %
• assertiveness skills	0.1 %
Client care	
• therapy skills (e.g. behavioural, cognitive, counselling)	39.5 %
• working with informal carers (e.g. parents)	23.6 %
• practical/clinical skills	17.5 %
• working in a variety of environments	8.3 %
• working with groups	8.2 %
• working individually with clients	5.1 %
Liaising	
• liaising with outside agencies	23.9 %
• liaising with the multidisciplinary team	20.0 %
Education	
• dealing with students	17.9 %

Table 6.1: Educational deficits identified within the first two years after qualifying *(n = 686)*

We also explored respondents' perceptions of their educational preparation by asking them to specify the areas in which they felt they needed additional educational preparation. Only a minority (12%) did not identify any deficits. The remaining respondents identified 51 separate areas of need. The majority of these were related to the care of users (27 needs identified by 59% of respondents) and the administration and management of services (17 needs identified by 48% of respondents); some respondents also identified teaching skills (three identified by 7% of respondents) (Table 6.2).

	Percentage of respondents
Administration and management	
• general and personnel management skills	35.3 %
– strategy planning	
– budgeting skills	
– managing/implementing change	
– managing people	
– dealing with difficult staff	
– disciplinary and grievance	
– delegating work	
• communication and research	5.9 %
– written skills	
– research skills	
• IT training	4.2 %
– computer skills	
– word processing/spreadsheets etc.	
• personal	2.8 %
– stress management	
Client care	
• clinical and care skills	33.0 %
– general nursing skills	
– care planning/assessment	
– therapeutic work	
– counselling skills	
– bereavement counselling	
– managing challenging behaviour	
– health promotion	
• mental health	12.0 %
– dual diagnosis	
– specific illnesses	
– forensic services	
– specific illnesses	
• specific conditions	7.0 %
– increased medical knowledge	
– epilepsy	
– autism	
– diabetes	
– cerebral palsy	
• update on developments	7.0 %
– legislation	
– NHS changes	
– current issues/practices	
Education	
• teaching skills and staff training	5.0 %
• nurse education	3.1 %
• dealing with students	2.0 %

Table 6.2: Main areas of educational need *(n = 357)*

6.3.1.2 Evaluation of current educational preparation

While most respondents criticised some aspects of their own educational preparation for learning disability nursing, most made positive comments about their initial education. A nurse who qualified in 1991 commented that *'[I] loved every minute of it! Best years of my life'* (0158/886). Respondents particularly valued the immediate contact that they had with service users. For example, one stated: *'The nurse training I received was excellent. We knew within the first couple of months whether the job was for us due to gaining immediate access to patients'* (0145/1173). While a nurse who qualified in 1983 commented that:

> *'My initial nurse education gave me a good all-round training in good basic care. It was work which was very much 'hands on', we were part of a team working on the wards with much of my knowledge gained from practical experience. Although my initial nurse training was within a large institution I gained many important clinical skills.'* (0363/769)

Another respondent noted that:

> *'[I was part of the] last group on "old" traditional training. [I] feel my experience and knowledge is superior to that of Project 2000 Nurses. [I] benefited from working whilst studying – learnt work ethic. [I had] responsibilities from the beginning. My role from mid 1st year was not supernumerary which gave me the opportunity of gaining invaluable experience.'* (0136/972)

Many respondents used their own education experience as a baseline for evaluating current educational provision, and clearly felt their own education had been far superior, as current education provided limited access to practice. One commented:

> *'When the nurse training school was part of the hospital site it allowed students to get to know staff/clients prior to practical placements. It also ensured students had frequent contact with people with learning disabilities. Current nurse training for RNMH seems far removed from the day to day practice of RNMH.'* (0247/423)

Another noted that:

> *'I valued the practical experience. Experience is gained by actually being "hands-on". I sometimes question if nurses training today get enough hands-on experience!'* (0224/1384)

Most respondents felt there was a major theory-practice gap in current educational provision:

> *'[The] previous 1982 syllabus seemed to produce "different" nurses. All had a wide variety of experiences with not being supernumerary. Many students I have had as a home manager and as a community nurse one wonders what is happening to "our" nursing. [They do not have much] practice following training – many seem to be using it as a stop to avoid working or collecting further education. I feel we have moved too far, too academic, caring/facilitation/nursing skills are being lost.'* (0231/1050)

When we invited respondents to comment on current education preparation, a minority (17%) felt that they did not know enough about current provision or had no contact with students and could not comment. A minority felt that the training was adequate (7%) and a small minority (<1%) felt that the balance between theory and practice was good. The remainder were critical. They did not feel that students were adequately prepared for practice. They identified specific skills shortages and a major theory-practice gap (Table 6.3).

	Percentage of respondents identifying limitation
Placement problems	
• too much theory and not enough practice	26.5 %
• limitation of current placements	24.0 %
• colleges out of touch with current practice	3.2 %
• students not involved in placements	1.4 %
Skills shortage	
• management skills	10.0 %
• care for users with specific needs	5.0 %
• clinical skills	4.8 %
• communication skills	3.0 %
• medication	0.7 %
Inadequate preparation for practice	
• unable to make student/nurse transition	7.8 %
• problems with students' attitudes	4.3 %
Education programme	
• problem of common foundation	4.1 %
• need more theory	2.1 %

Table 6.3: Perceptions of the limitations of current educational preparation

6.3.2 Current students, future nurses

Current nursing students can be seen as the primary consumers of current nurse education, and through our focus groups we explored their motivations, their perceptions of their learning experience and the extent to which they felt ready for practice.

6.3.2.1 Purpose of nurse education: developing and enhancing the skills of learning disability nurses

As we noted in Chapter 5, students accept that the main aim of their nursing education is to enhance or develop their skills as learning disability nurses. How they evaluate their education depends on how they define the role of the learning disability nurse and we start with students' definitions of the roles of qualified nurses.

Generally the participants in our focus groups did not find it easy to specify the role of the learning disability nurse: some either used tautological definitions or suggested the role was context-specific. For example, one indicated that if someone asked her 'what is a learning disability nurse?' she would reply: *'We're specialist nurses that deal with people with learning disabilities and we look at social and health skills. We're special nurses'* (1/F). Other students pointed out that the role of the learning disability nurse is difficult to define and the type of role undertaken depends very much upon the location of practice. As one diploma student said: *'It's really difficult to describe because it depends where you're working and what you're doing. Everywhere's a bit different ...'* (2/3). Another commented:

> *'Because our role is so broad, depending on what area we work in – whether you work with children, community, forensic, whatever.'* (8/3)

When pushed, most groups were able to provide a more detailed specification of the role of the learning disability nurse. This included a variety of elements, acting as a representative, providing direct care, managing services and providing education, especially for other care staff.

Most groups agreed that an important element of the learning disability nurse's role was acting as an advocate for people with learning disabilities. One group placed great emphasis on this role. They discussed their role as advocates and how they would do:

> **Student A:** *'Anything, everything I can to help them to speak out, getting things, anything, everything I can to help them to speak out and get what they need done. That's how I see it. I think you have to be quite a fighter in this kind of job.'* (2/4)
>
> **Student B:** *'You have to be very strong. You have to be able to stand up and say what's right and what's not.'* (2/3)
>
> **Student A:** *'You have to be able to confront it.'* (2/4)

Other learning disability nurses' roles included *'enablement and empowerment'* (3) of people with learning disabilities in relation to *'community participation'* (3). Students also spoke of *'encouraging independence'* (3), and allowing people with learning disabilities to make choices about their lives.

All the students acknowledged the *'broad specification'* (7/1) of the learning disability nurse's role and the importance of providing care and support for people with learning disabilities, especially providing health care. When one was asked what she would say if asked to define her role she replied: *'Health needs. I think you just have to keep battering that at people'* (8/2). Another said:

> *'You're there more than anything to pick up on health problems. I know there was a time when it was all about normalisation, empowerment but I think that we're swinging back now towards looking at health issues, additional health problems.'* (7/1)

For many students health care encompassed all aspects of care. One described health care in the following way:

> *'Holistic – it's psychological, emotional, all the cultural, physical – that's what I believe health is and I think that's what my job is. To make sure that someone with a learning disability has experienced what they need with regards to holistic health.'* (2/4)

The students who took part in the focus groups felt that the nurse has a broad role as a therapist for people with learning disabilities and their families. One qualified nurse argued that in her own practice area, she and her colleagues: *'work with families on a one-to-one. We do group work as well ...'* (8/2).

6.3.2.2 Nurse as a representative of people with learning disabilities

In addition to meeting the health needs and promoting the health of people with learning disabilities, students identified other important roles. While they felt that the main roles of learning disability nurses were to act as advocates for people with learning disabilities and also to provide them with care, they acknowledged that to do this nurses needed to be able to manage services and to provide leadership. One commented that a nurse ha... be a *'good leader'* (2/1). The students specifically identified a role for nurses in the management of change. They also identified a main part of the nurse's role as *'co-ordinating care for people with learning disabilities'* (2/3). They saw this co-ordination as working within the context of the multidisciplinary team, as two students pointed out, nurses were responsible for:

> **Student A:** *'... co-ordinating it all ...'* (2/4)

Student B: *'Within a multidisciplinary team.'* (2/3)

Student C: *'Basically, yes. Just getting it done.'* (2/4)

Part of the leadership role included teaching care workers and other members of staff. One student stated:

> *'I believe my job is to show care workers that perhaps haven't had the training or get them the training so that they can learn about things so that they're making sure that these things are done.'* (2/4)

Since students expected their education to develop their skills as learning disability nurses, they clearly expected these programmes to provide them with the skills to empower, to provide care, to manage services and to educate. In the remainder of this section we examine whether these expectations were fulfilled.

6.3.2.3 Negative consequences: isolation and marginalisation

While choosing a learning disability programme was a positive choice for students, it was one that for many had negative consequences. Many, especially pre-registration students during the common foundation programme, felt isolated and marginalised within their educational institutions.

This marginalisation was linked to the small size of most cohorts. Learning disability was the smallest branch, as one student on a 'large' learning disability programme noted: *'There's so few of us. There was 30 general students and there was eight, six, seven, eight of us at different times'* (4/4). Even on a post-registration nursing programme one student found that: *'Well, out of 100 people on the course there's four learning disabilities nurses'* (8/3). Another commented that she: *'felt marginalised in all the classes I took'* (4/2).

Some students felt that they had to constantly remind other students of their presence and this created a great deal of pressure. This was illustrated by one post-registration student who said:

> *'You just feel like you've got to keep talking or you've got to keep saying something just to show that we're there and that, you know, and that's a lot of pressure on you isn't it?'* (8/2)

The students also reported other examples of why they felt that being in groups of such small numbers was a disadvantage. They cited instances where the students on other branches would protest about certain issues and because of their group size their complaints would be heard, whereas it was easier for people to ignore the concerns of learning disability nursing students. One example given was an occasion when the learning disability nursing students were on placement without a mentor who was a qualified learning disability nurse:

> **Student A:** *'And that's a problem with numbers again. It's 'cos there's so few of us. The ones on adult, if they hadn't got a mentor they'd be jumping up and down.'* (6/3)
>
> **Student B:** *'And you can jump up and down all you like 'cos you don't make enough noise when there's only two of you.'* (6/1)

Some students also felt that because they were often the minority within the group – particularly during the Common Foundation Programme (CFP) – the focus of the lectures and the lecturers was usually on adult health nursing. This was a particularly strong theme of the student focus groups. One student said: *'All the examples they give in the lectures – it's for adult nursing'* (1/f). Another student in this group commented that:

> *'There was a heck of a lot which gave guided examples based on adult placements which were the majority, you know – "when you're on the ward look out ..." so you automatically switch off from them.'* (1/m)

These thoughts were echoed by a student on a diploma programme, who said: *'everything just revolved around general nursing. It made you switch off a bit and think well, what am I doing here?'* (2/2). One student felt particularly strongly about the type of teaching she had received during the CFP:

> *'I remember spending so much time in the CFP being so angry. We were all so angry weren't we about the teaching we were getting, knowing that it wasn't what we needed to get. It was just like this isn't right. We were sitting in so many lectures and we weren't recognised at all. There were lecturers that had been asked to come and give us a lecture and they obviously hadn't been told it was a mixed group and they just gave a lecture to a group of hospital nurses. It was very frustrating.'* (5)

Several students commented on the apparent lack of learning disability nurse lecturers within the CFP. They felt that their teaching was usually conducted by lecturers with general nursing backgrounds, as one commented: *'the tutors we had didn't even know anything about learning disabilities'* (5).

Similar problems arose in relation to the setting and marking of assignments by lecturers without a background in learning disability nursing. One group of students talked of how they were asked to relate their assignments to their particular branch but faced problems when they needed to seek help because: *'they [lecturers] don't know enough about it themselves. A lot of the time you're left to do it on your own'* (6/1). Other examples included a student who submitted an assignment that was subsequently:

> *'... marked by a general nurse tutor who didn't know anything about it and I'd focused all my work on learning disabilities and someone marked it and they didn't have a clue.'* (5)

This feeling of being marginalised was not confined to students on the pre-registration programmes. Others on post-registration specialist practitioner programmes said that being in the minority and having difficulties in getting themselves heard made them feel like a *'Cinderella service'* (8/2,8/4). They pointed out that they were always at the bottom of any lists and felt that this echoed their experiences as qualified nurses about being undervalued and having to justify their existence.

One of the students on a combined learning disability nursing and social work programme also felt marginalised during the nursing part of the programme, but had a different experience when it came to the social work elements:

> *'I think that's the difference between the nursing and the social work though, because all the time in [nursing] lectures we weren't included. It was all clinical this and that – hospital-based. But it came to social work and you were valued as a learning disability nurse and your contribution was valid. We were excluded all the way through the nursing – lectures, practical skills – that was a major difference we were actually valued for our experiences [in the social work part of the programme].'* (5)

Several students said that they felt closest to the mental health nursing students, feeling that they were in the best position to empathise with how the learning disability nursing students felt. A joint nursing and social work student commented:

> *'We always felt quite an affinity with the mental health branch as well coming from looking at, taking the person holistically, not treating and curing patients.'* (5)

6.3.2.4 Branch learning: getting past the common foundation programme

Generally the pre-registration students felt that their 'learning disability' education only started when they entered the branch programme. Only one group commented positively on the CFP, describing it as *'an excellent foundation'* (6/1), but even they noted that: *'it's a shame there wasn't a little bit more that was learning disabilities'* (6/1).

In the branch programme students expected to be taught by specialists and to learn about learning disability, and were disappointed if this did not happen. For example, one student on a joint nursing and social work programme felt that students *'really started learning'* (5) once they left the CFP. While another disappointed student stated that:

> *'Once you get into your branch I thought, I expected the course to be more learning disabilities and that my, the work that I would be doing would be orientated towards learning disabilities and it's not.'* (6/1)

Students felt that the branch programme offered them real learning opportunities. The general consensus was that: *'the lecturers give you the tools to work with'* (1/m) leaving it up to students to *'go out there and read'* (8/3). The students all agreed on this and argued that: *'if you've got to listen to someone and take notes and go away and do little exercises you learn a lot more'* (3/2).

Generally, students commented positively on the learning opportunities provided in their branch and post-registration programmes. One identified the area she liked most as: *'Learning. The lectures. I like all of it. I find it stimulating'* (2/4). She went on to say that she liked:

> *'... how it challenges the way you think with regards other people and yourself. I found there's been quite a few times where I've had to really look at myself as a person through lectures or all sorts ... I feel like I've grown up a lot and seen a lot more about life in general.'* (2/4)

A student on a shortened programme had also enjoyed her studies. She said: *'I've enjoyed getting my head around working again. I've enjoyed doing my assignments'* (7/1). This student went on to consider how the programme had *'got me thinking again'* (7/1) and added that all qualified nurses should have the same sort of challenge since: *'as qualified nurses we tend to, sort of, sit back and we don't do anything to a certain extent'* (7/1). She also considered that the PREP requirements for updating did not go far enough, and did not present nurses with as much of a challenge as they should. Another post-registration student agreed and said that the programme: *'gives you a boost, an energy boost nurses need. They tend to get a bit stale'* (9/6).

In addition, a number of students commented on how the programme increased their personal confidence, especially as a result of undertaking certain methods of assessment. As the following students commented:

> **Student A:** *'I think the branch part is very good ... having the conversations and doing the presentations as well. I think it's very good 'cos when I first started I was very, very shy. I would not have talked to you. I feel more confident in myself.'* (2/1)

> **Student B:** *'I think that's something I can definitely say as well. Having to get up and do presentations and push yourself forward. And going on placement and having to make the effort and sort of achieve your learning, you know. It does give you a lot of confidence.'* (2/3)

Students' main criticism of branch and post-registration programmes related to practical problems that prevented them learning, especially the perceived disorganisation of many programmes. We were given many examples of this and students on three programmes in particular felt strongly about this issue. They were especially concerned about the way that lecture times were organised. Several felt that more consideration should be given to students,

particularly in relation to cancelled lectures. One, who lived 80 miles away from her educational institution frequently travelled in for lectures only to find that: *'the lecture's been cancelled and you haven't been informed and then you've got to travel all the way home again'* (2/3). The same student also pointed out that if a lecture is cancelled *'it doesn't get covered again'* (2/3). The position of the lectures in the overall programme was also noted to be a problem occasionally. Several students reported that they frequently had lectures that were relevant for their assignments after the submission date had passed. Another reported being lectured about how to give injections several weeks after actually administering injections on a placement. They thought this problem could be resolved by improving communication between lecturers, administrative staff and placement areas.

Students on shortened programmes who were adding a learning disability qualification to another nursing qualification found their programmes did not take into account their distinctive learning needs. They had joined other learning disability students at the start of their branch programme. This meant that:

> *'I found joining the group, to a certain extent, a bit tedious because already being a general nurse anyway I found some of the stuff they covered so incredibly basic … you cover a lot of the basic physical stuff as well which I think you cover at a far higher level when you're doing general [nursing] training anyway.'* (7/1)

6.3.2.5 Learning in practice

While students acknowledged the learning opportunities offered in the educational institutions, they felt that their real learning took place in practice placements. When they were asked to identify the things they liked most about the programme, practice placements were the most frequently cited. Students enjoyed being out in the workplace where they were able to put what they had learned in the classroom into practice. As one said:

> *'The thing that I've enjoyed, I think, is the placements. It's putting into practice what you've learned in the lecture theatre. Although I really enjoyed learning about them [the theories] it's actually applying them in a practical sense.'* (1/f)

One student on a joint programme summed up the students' feelings quite well: *'Some people have had excellent placements that have really helped them. Others haven't'* (4/4). One of her fellow students added *'at the end of the day sometimes you feel that, whether the placement is positive or negative you learn something out of it'* (4/2).

Students felt that placements in whose selection they had been involved provided particularly valuable learning experiences; post-registration students who were able to select their own placements were especially positive. One group had the opportunity to arrange *'five days' alternative practice'* (8/2) which they could spend wherever they chose. One nurse had chosen to spend time in a head injuries unit, another chose to work with children *'because I don't have any contact with children now'* (8/4) whilst another wanted to work in a school. Similarly students on one of the pre-registration programmes enjoyed a period each summer when they were allowed *'time to go and visit places that you aren't allowed to visit when you're in placement'* (2/2). The students viewed this part of their programme positively because it enabled them – as one pointed out – *'to organise anything you want to achieve, anything you want to do'* (2/3). One post-registration student felt happy about her placement experiences: *'Mine's been quite positive. I've really enjoyed mine. It's given me lots of ideas that I can bring back to my trust'* (8/1).

As with learning in class, students felt that practical problems often prevented them making full use of the learning opportunities provided in practice. They felt that many placements were too short and inadequately prepared, there was a lack of choice and variety and they were not adequately prepared for or supported in practice.

The students we interviewed expressed concern about the length of their placements. Several pointed out that: *'a lot of the time you get quite short placements'* (6/1) and such short placements did not allow them to follow the progress of their clients. As a student noted:

> *'There's no continuity either. If you went in [for] two days you couldn't follow your patients so you never got complete care. You just got bits and bats.'* (1/f)

This issue arose quite frequently in the discussions. Many students pointed out how the short time they spent on each placement meant that they *'can't get completely involved'* (6/1) because time does not allow them *'to build up the sort of relationship that you need with the clients'* (6/1). This student went on to demonstrate how, on her community placement she missed out on valuable experiences because:

> *'I can't actually go into some of the homes because it's unfair to expect them to see me, like, once. I come on one visit and for them never to see me again.'* (6/1)

When arriving in their placement areas some students reported that often they were not expected. An example given was of a recent placement where the staff *'didn't have a clue what they should be doing with me'* (1). One student said:

> *'I remember when we started our nursing placements – we were following on from general nurses who had been in learning disability placements – and it was awful because we were so discriminated against because they thought we were general nurses and they were really on our cases because they had just gone in and damaged all these placements and we had to go in and say no, we really want to work with this client group and this is what we are trained to do.'* (5)

Other problems arose in relation to the assessment of practice placements. Students frequently reported that many practice assessors were not clear about how to assess them and what to expect from them: *'You can go in on placement and they really don't understand why your objectives are, what they are sometimes and it can be difficult'* (2/3).

Students did not feel that they had any choice over their placements. Students on one programme said: *'we just got told where we were going, didn't we?'* (1/f). This sometimes created practical problems – particularly for students who did not live close to the educational institution. A student on a diploma pre-registration programme noted that: *'They don't seem to know where you live and they'll send you miles away'* (2/4).

It also limited learning opportunities. One reported that:

> *'They [the educational institution] didn't take into account your previous experiences so you could have worked in a day centre for three years and then gone and done another six weeks whereas it may have been of more value to do a community placement.'* (5)

However another felt that:

> *'I've had placements that have actually been very useful for me and then I've also had placements where I've actually had to work my way around things to make the objectives.'* (4/2)

Although in the programme documentation the majority of educational institutions pointed to the wide variety of placement areas that the students experienced, the reality, according to the students in our sample, was very different. One group of third-year diploma students stated their placement experience to date was limited to four learning disability placements within two neighbouring homes. As one said:

'Of all the learning disabilities placements I've been on I've only been to two places. I've been back to the same house twice and I've been back to another house twice so I've only seen two places in my three [years] ...' (2/2)

When students were asked whether they felt that they were prepared prior to going into the placement areas, several reported that they were not. One said:

'No, I don't think we're given enough, what's the word? Emphasis on what you need to achieve. We're given the booklets but they don't really go through them ... You know, they're not saying before you go out on placements, they don't kind of say well you ought to try and achieve this goal on this placement, this objective.' (1/f)

A number of students considered there was a need for better links between the educational institution and placement areas. They often reported feeling unsupported in practice settings and those students at one institution felt that it lost touch with them once they were on placement:

Student A: *'We've just done a nine-week placement and I didn't see my link tutor.'*

Student B: *'I've had a visit off a link teacher once in the whole course.'*

Student C: *'Yes, the same for me.'* (1)

Even in their placement areas few students could expect to work alongside registered learning disability nurses. Although the guidelines clearly state that this is a requirement at least for several shifts each week the students reported that they often did not receive even this amount of contact. The students on one particular programme all agreed that they did not even meet a learning disability nurse until they reached their branch programme: *'I was in my third year before I actually met a learning disabilities nurse'* (6/1) whilst a student at another institution said:

'I think there are some excellent learning disability nurses. I haven't met many to be honest with you. In the whole time I've been doing this I've met about three.' (2/4)

Given the placement limitations, which most groups identified, it is hardly surprising that they identified a theory/practice gap. Many students cited examples of the gap between theory and practice. Most of these related to, as one said: *'the sort of things that perhaps in practice they're not done as they should be'* (7/1). One group considered how their lecturers taught them about enabling people with learning disabilities to make choices but showed how, in reality, such choices were often restricted by the responses of other care workers. They talked about a client who wanted to buy a white bag to match her shoes and the response of one senior care worker who insisted that: *'she will not have a white bag, you will get her a brown bag or a black bag'* (2/2).

Other areas where students felt an element of conflict between what they were taught and what actually happened in practice related to moving and handling. This was cited as an example by students from different programmes. They related how they were shown the correct methods of moving and handling and the use of hoists but said that once in practice they saw many examples of bad practice. The students revealed that they felt uncomfortable with challenging staff about bad practice since many of the culprits had *'been in the job [for] 30 or 40 years and you're only a student'* (6/1). The students also lacked confidence about introducing the new concepts or ideas they learned in college into practice areas. One said that that was:

'... because the people out there [in practice] – especially if they've been qualified for a while – they don't know what you're doing and ... they look at you a bit blank.' (1/f)

Most students agreed that much of the teaching they received in the classroom or the lecture theatre was very idealistic. As one said:

> *'I think there can be a big gap between – because we're taught the current developments, the ideal standards – and there is a big gap between that and reality.'* (1/m)

When asked whether the theoretical side of their programme matched what happened in practice, one group of students agreed that although lectures were idealistic, so long as everyone was aware of that it was not a problem. The idealistic picture painted by the lecturers in the classroom was not always seen as negative. Students generally appreciated being taught the ideal so that they could then, *'go somewhere and think well, it shouldn't really be like this'* (1/f). Most students accepted that *'there's always a gap'* (3/2) but were keen to point out that because they were aware of it, this did not create too many problems for them.

6.3.2.6 Ready for practice?

The students were asked how they felt about approaching the end of their programmes. The responses of the pre-registration students were quite similar. Although many reported feeling *'nervous'* (6/1, 1), or *'scared'* (4/3) there were also a number who were *'looking forward to it'* (4/2), *'ready'* (1), and keen to begin their first posts. Several felt quite confident about taking on the role of a qualified learning disability nurse, although they did point out the shortfalls they had mentioned earlier in relation to their training and education. Only the student on the shortened programme felt that her programme *'prepares you to do anything in learning disabilities that you want to do'* (7/1). She was a very confident student whose view was in the minority.

The post-registration students were clear about how their programmes had changed or would change their practice. All agreed that as a direct result of undertaking their programmes they were *'more confident'* (8/1,9/4) because they now had the knowledge base to back up their practice. They spoke of the programmes giving them a broader *'outlook and knowledge-base'* (9/6) which in turn equipped them with the confidence to go back into their practice areas and start making changes. They felt more able to confront their colleagues when faced with certain issues, since they considered that they had the knowledge base to support their ideas and opinions, whereas they had felt unable to do this before the programme.

The post-registration students also pointed out that they now had the confidence to teach others. As one said, she could now: *'explain to others why I'm doing what I'm doing rather than just doing it 'cos I know it's right'* (8/3). Another added that having the knowledge increased his confidence because it: *'gives you the clout to say this is good practice'* (9/6).

Pre-registration students were invited to comment on whether they felt prepared to practise at the end of their programme. Only one said that she was confident enough and ready to take on the role of a qualified nurse. Most of the others agreed with the student who said that she felt *'ready in some ways but not in others'* (1/f). Many were able to identify areas that they felt needed further input in terms of education and practice, however they generally accepted the view of one student who said: *'I don't think anyone on any programme ever feels prepared.'* (4/1). This student went on to say:

> *'You've got to wait until you get out there, really. That's going to be the biggest time to start, you know, learning. I think we'll learn a lot more even then than we have done in these three years.'* (4/1)

In a similar vein another student likened the experience to learning to drive. She said that: *'you only really learn to drive when you do it, when you've done your test and you're doing it'* (1/f).

One student pointed out that it was difficult to say whether you felt ready to practise since: *'it depends what job [you take]'* (5) or, as another said: *'until you know the client group you're going to be working with'* (4/1). It was interesting to note these views, since most programme

literature outlined how the programmes were preparing practitioners who would be able to work in a wide variety of settings with a wide variety of client groups. The students generally felt that once they were established in the area where they would be working they would then begin to learn the specific skills they needed.

Students identified a number of specific areas in which they felt inadequately prepared for practice. These included clinical skills, meeting health needs, communication skills and management skills.

Students were concerned that their clinical skills were not adequate for practice. A joint social work nursing student commented that:

> *'I feel very nervous about clinical skills. I don't feel like I've had nowhere near enough experience and it scares me to think that I'll be qualifying shortly and I'm not confident to do clinical skills really.'* (4/3)

Examples of clinical skills included the administration of medication, the care of someone having gastrofeeds and the giving of injections. These areas were cited by a number of students. One said: *'I'm always nervous about ... medication'* (4/1) and another spoke for many when she said that she had absolutely no confidence in giving injections. She confessed she did not know how to draw up an insulin syringe and administer the injection even though: *'by now it should be second nature'* (4/3). This issue arose on a number of cases and one student pointed out the thoughts of many when she said: *'you could have come all the way through and not given an injection quite easily'* (4/4).

Students also considered that they were unprepared for meeting the health needs of people with learning disabilities. The student who was general nurse trained felt quite strongly that learning disability students were not prepared for this part of their role:

> *'I don't think there's enough "general" nursing around learning disabilities ... I think there's a lot more around health that learning disability nurses have to get into.'* (7/1)

She went on to say that she was grateful that she had a background in general nursing since it was this that had prepared her for many of her learning disability nursing roles.

Another group of students considered that they needed *'to focus more on health issues'* (1). This group felt that the programme concentrated too much on, as one said:

> *'... sociology and psychology and all that sort of side of it. Social, you know, social living and things. But there isn't much on health needs and health care.'* (1)

A student on another programme agreed. She said that she felt unprepared to meet *'the physical side of somebody'* (2/4).

Communication skills were identified by a number of students who felt they need more input into this area. Several students identified the need for *'practical communication skills'* (4/4). One student pointed out that in the CFP he learned a little about Makaton but added that he thought *'more would be useful in clinical work'* (2/1). Another considered that she and her fellow students were expected to pick up communication skills from their practice but felt that: *'because we've jumped around so much'* (4/4) they had not had the time to develop their skills within one area. The same student felt that: *'I think we should have a lot more input on that [communication skills] 'cos it's such a big area – particularly for learning disability nurses'* (4/4).

Another area identified as needing more input was that of management and leadership skills. One student considered herself *'to feel ready client-wise'* (1) but was anxious about *'taking on the extra responsibilities'* (1) such as managing a unit and the staff. Another student in the same group added that she was worried by:

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> *'... the thought of being a leader as well. We're used to being under a leader with someone above us, but once we get out there we're going to be the leaders and have all that responsibility and it's quite scary.'* (1)

Students in another group reported that the input they received on managerial and leadership skills was minimal and they felt that they were expected to develop these within their placement areas. They pointed out that their potential for learning about management and leadership depended on, as one student said: *'what kind of practice facilitator you get on placement as to whether you actually achieve a great deal or not'* (2/3). Other students on the same programme also discussed how they felt that management and leadership skills were not something that they were taught directly. As one said: *'The way I see it, basically, I have to sort it out for myself'* (2/4). Another added that she learned her management skills not from her teachers but from having:

> *'... watched every time I've gone out on placement to see how people are managing – the sort of skills that they're using and how the staff are responding to that.'* (2/3)

She said that management and leadership skills are *'something I think that if you're not going to go out there and get yourself you're not, it's not going to happen'* (2/3).

One group of students also pointed out that as managers they would need to have knowledge of the different services and this was something they did not feel they possessed. As one said:

> *'[As] you're the gateway to these services you need to know what is out there and what is suitable. And I don't think, although through your placements you see certain services, you know, you don't know everything that's around. Scary.'* (4/1)

Other areas that were highlighted by one group of students included breaking bad news and writing care plans. One student considered how when she was asked to write a number of care plans her practice teacher was: *'appalled that we hadn't been taught how to write a care plan'* (5).

6.3.3 Comment

Both students and nurses expressed concerns about the extent to which current nurse education was preparing students for practice. While nurses were critical of the education they had received and identified areas in which they had not felt prepared for practice, they felt that they had had more opportunities to develop appropriate skills in practice. They felt that both the length of the CFP, with its perceived general nurse orientation, and the limitations of placements in the branch programme meant that nurses completing current pre-registration programmes had less opportunity to develop appropriate skills. Current students were also concerned about their limited opportunities to develop practical skills and did not feel confident that they were fully fit for practice at the end of their programmes.

6.4 Indirect consumers: employers, users and families

While current and former students were the primary consumers of nurse education, employers, users and families were indirect consumers, as they make use of the services of qualified nurses. Any limitations of the educational process will have a major impact on them, employers may need to make good limitations with additional training, while users and families may receive inadequate or inappropriate services.

6.4.1 Employers' views of 'fitness to practise'

We were able to interview employers who took students from seven of the programmes that were included in the more detailed part of our study. We explored with them their

involvement in the programmes, their assessment of the strengths and weakness of the programmes and of whether students were fit for practice at the end of their programme or needed additional training.

Only two of the employers felt they had close involvement in the design and development of the curriculum. One NHS employer who employed students from a pre-registration diploma felt his involvement was particularly close:

> **Interviewer:** *'So what kind of input did you have?'*
>
> **Employer:** *'Total input. I was involved with the regional education consortium plus [educational institution] in devising the new nursing pre-reg. branch nursing programme.'*
>
> **Interviewer:** *'How did you get involved?'*
>
> **Employer:** *'I was asked. Directly asked as the senior nurse here. There's other representatives from the region that [institution] covers.'*
> (NHS employer, pre-registration diploma programme)

One manager in an SSD participated in all aspects of his local social work nursing pre-registration degree from the interview and selection of students through to helping graduates find employment:

> *'I feel as though I've had quite a significant, ongoing interest in [the programme] and always wanting to know what the outcomes are for each year and also been involved in the interviewing as well for the students coming forward and making applications. So all round also having the students on placement in some of the areas that I manage as well. So I think it's quite a good understanding of everything that goes on … I know within [department] at least one person who's come off the programme. [I do] references for them as well.'* (Social services employer, joint pre-registration degree programme in nursing and social work)

The remaining employers did not have close involvement in the programmes nor in most cases did they expect to have. Some had established link-posts, but this was often not very effective:

> **Interviewer:** *'Do you have any input into curriculum design or development of the curriculum?'*
>
> **Employer:** *'No, I don't. No we don't have input into that. We do have a student nurse co-ordinator on the team with G-grade responsibility and she sort of looks at allocation of placements to students. But we don't have any direct involvement on the curriculum.'*
>
> **Interviewer:** *'Would the opportunity be there if you wanted to?'*
>
> **Employer:** *'I'm not so sure really because the involvement that we've had with the [institution] is very sporadic really. I mean we used to have meetings whereby as a student nurse co-ordinator this G-grade nurse could go and hear the views and concerns of the students that are coming onto placements. But I feel that's [been] lost, that's lost it's way really.'*
> (NHS employer, pre-registration degree)

Most employers did not have the opportunity to influence the design and delivery of the curriculum so that it reflected their specific service needs.

Even though employers did not feel involved in the development of programmes, they did feel that they had a good knowledge of individual programmes and felt able to assess the strengths and weaknesses of the curriculum. They also commented positively on the

opportunities that programmes provided for students to be aware of current developments and to develop appropriate values:

> **Interviewer:** *'So the people that you've employed from the programme – what do you see as their particular strengths?'*
>
> **Employer:** *'Let me think. Right, their strengths. They're very aware of the rights of individuals. I suppose it's more to do with the socialisation and things like that. They're very up to date with current initiatives and things that we should all be looking at so I suppose that's one of their biggest strengths.'* (NHS employer, pre-registration degree)

Most employers felt that the programmes provided students with opportunities to develop a good understanding of learning disability. For example, one NHS employer described the students in the following way:

> *'[The students have] got a lot of theory. They've got a lot of, sort of like, knowledge. I think the theory is there. They're strong on content but not necessarily always strong on practical skills. But certainly the students that we've had through on pre-reg. have been very well motivated and learning to look at alternative ways of working.'*
> (NHS employer, diploma pre-registration programme)

An employer from a children disability team jointly funded by a NHS trust and an SSD commented favourably on the knowledge of a recent graduate from a joint social work pre-registration degree programme:

> **Interviewer:** *'From your experience of the students you've employed from this programme, what do you think are their particular strengths?'*
>
> **Employer:** *'The student that we employed, I think she came out on placement with us. She has a very good knowledge base but I think that's also down to previous experience prior to training. She's actually been able to take up anything new and learn it very quickly and she's now, I'd say, a very skilled practitioner already and is very willing to learn anything new.'* (Employer, joint funded service, joint pre-registration degree programme in nursing and social work)

While this employer was impressed with her employee's skills, all the others expressed serious concerns about students' skill levels. They felt that they were not adequately prepared to practise. One private sector employer who recruited nurses for a nursing home specialising in caring for people with learning disabilities and mental health needs commented positively on the utility of a post-registration programme in learning disability but was highly critical of pre-registration education:

> **Interviewer:** *'So having done [the post-registration programme] you're quite familiar with the content. Can you tell me what you feel are the particular strengths of students who have completed the programme?'*
>
> **Employer:** *'I think, overall just a more general awareness of the mental health side of our care really. Because we're a nursing home for people with learning disabilities who have mental health needs, I think when people came back they weren't so keen just to look at the learning disabilities side of care using the assessment forms and techniques that we use now – they were more keen to look wider and look at other resources and other facilities that maybe they didn't really know about beforehand.'*
>
> **Interviewer:** *'In general do you feel that [newly qualified nurses] are prepared for practice in your area?'*

Employer: *'You want me to be absolutely honest? No I don't. I really don't but then the upshot of that is that we have to put in six, well forever I suppose, but certainly six months' intensive support and our own training and at the end of that six months I would say yes, they were probably about at the same position that traditionally trained nurses were when they were doing the 1982 learning disability syllabus. But maybe they've got other skills. So if I'm talking from an employer's point of view and say when it comes down to practicalities there's no chance of them being accountable on a shift for at least six months then from an employer's point of view that's difficult isn't it? But if I'm talking as a nurse, which I am then in a way the other areas, their enhanced knowledge, their enhanced skills in other areas probably over a year makes up for that. The fact that they're able to access information, access other packages of care, other models, other ways of working far more easily than perhaps a traditionally trained 1982 syllabus RNMHs were. I think if you look at a year down the line it probably balances itself out but certainly initially I think the gap's quite wide.'*

(Private sector employer, pre-registration programmes)

Some employers were concerned about individuals' ability to apply their knowledge. For example, an employer in a jointly funded NHS/social services team commented:

'I think from my experience of talking to the students who have been here [have] a lot of emphasis on the social work side, antidiscriminatory practice. We often say people can talk about antidiscriminatory practice but it's actually how [they apply it] … you can talk and talk about it but people need to have that practice of knowing that that's how you act, or not.' (Employer, joint funded service, joint pre-registration degree programme in nursing and social work)

Another NHS employer felt that the students' lack of 'hard' practical skills reflected their tutors' bias towards 'softer' skills such as advocacy. A NHS employer who employed students from a joint social work/nursing degree programme identified a serious theory/practice gap that resulted in a skills shortage:

Interviewer: *'Do you think that their training or education prepares them for practice?'*

Employer: *'Again I think there's too much theory. I think there's not enough practice to substantiate what they've learned theoretically. So I think, again, if the balance was, sort of, swayed again in terms of more practice then I think that would, sort of, equal it out … We've had some people – other students – who've been on the joint programme and they've been very poor in terms of the practical skills that nurses have. We had one particular person who was absolutely frightened to death of doing depo injections and that was quite a learning curve for us really – looking at how poor the practical skills were for that particular person.'*

(NHS employer, joint pre-registration degree programme in nursing and social work)

Another employer indicated that students were not prepared for management, especially fighting for resources:

Interviewer: *'Do you think that learning disability nurse training prepares them for practice?'*

Employer: *'I don't think it did no. Certainly not because it's a changing world out here and I don't think [the programme] took into account some of the difficulties the you face in trying to get a service for people, the*

resource implications, finances one thing and another. It's a very difficult world to work in so I don't think that it did but again, hopefully, that will change with the new syllabus.'

(NHS employer, pre-registration diploma programme)

All employers recognised the limitations of students' preparation for practice by providing in-house preparation in the form of specific induction training plus mentorship or supervision. Some emphasised care skills but one key area included was management, especially in areas such as health and safety and risk management.

Interviewer: *'Do you have to give them any sort of specific extra training so that they are prepared for working with you?'*

Employer: *'Well we cover a lot of risk assessments. They have very little experience the ones that we've had through doing risk assessments. So going through those is probably something that I think we have to do with most students. I think they get a bit of a shock ... I think there's a bit of a reality check for people when they come to us.'*

(NHS employer, pre-registration diploma programme)

In some cases the employers appeared to provide what amount to a crash programme in key care skills:

'We actually do our own induction and everybody goes through. [It covers] the usual things like health and safety, moving and handling, first aid ... the induction covers – the value base, epilepsy, basic care [including] hygiene, diet, all the usual things that are quite important to people. However there's a big issue lately in the press about older people in care not being taken care of. Communication, basic first aid – the actual first aid is done by the ambulance service – engagement skills.'

(NHS employer, pre-registration diploma programme)

One private sector employer who recruited nurses to work in a nursing home provided a six-month 'intensive support and training' package:

Interviewer: *'What would that training consist of?'*

Employer: *'You know, I really don't want to sound patronising to the new nurses but really the practicalities. Things like being confident to give injections, being confident to give out medication, being confident to make decisions and stand by those decisions, confidence with epilepsy, confidence with challenging behaviour. Maybe the nurse has the skills but maybe it's practice that they haven't had.'*

(Private sector employer, pre-registration diploma programme)

6.4.2 User perspectives

The three focus groups composed of people with learning disabilities readily referred to student nurses encountered within care or service facilities. Others had been involved with training programmes while some had no such experience.

The self-advocacy group appeared to be a focus for education and the day centre itself appeared to provide a placement for nurses. One participant explained: *'We had trainee nurses come round our centre for a week to see what we do and that ... some of them came to our meeting to see what we do'* (6/6). The nurses were described as finding out about self-advocacy, *'all different things that happen in our centre'* (6/6).

One participant explained their feeling that control of such placements was largely in hands of those in the educational setting:

'It comes in waves, doesn't it? Sometimes there have been times when there have been three or four trainee nurses that have come to talk here and maybe [for] six months nothing will happen and then someone will come again. It's not a regular thing. It depends on the programme tutors and whether they see it as important; we do one quite regularly for teachers, but the other one for nurses, the last one we did for people in mental health, the programme tutors thought it was important.' (6/6)

In this group no one said they had been involved in developing any programmes or programmes at the college (6/7). However, on occasions participants from the self-advocacy group had attended a local higher educational institution:

'We have a couple of times gone to the university to give advice to nurses, doctors and students. We have been complimented and people have been shocked about what we do and how we go about it. We do training for the social services in the advocacy field for about three years now.' (6/6)

In another group, participants reported less contact with educational providers. Asked if they had been asked to contribute to student training, they responded:

User A: *'Not very often.'*

User B: *'No.'*

User A: *'Not very often but if they asked me I'd probably come.'*

User C: *'Yes.'*

User D: *'And me as well.'*

Interviewer: *'Has anybody ever been?'*

User C: *'No.'*

User E: *'I don't think so.'*

User A: *'I've been ... when Andy goes round the community, I've been to Chris's place with him ... He took me to Chris's place when he had to see him and that, but I didn't go in. I waited outside ... I suppose I could have gone in if I wanted to but he didn't ask me so I didn't.'* (8/13)

From the other group interview came similar willingness to be involved in professional education: *'I mean we could and it would be nice if we did help like. I think it would be a better idea'* (1/11). However, group participants also remembered individual student nurses who appeared to have spent time on placement within their day centre:

'I can remember there was this other one ... He was like always, you know, playing football and cricket out there, he was. He was nice to talk to. He's a nice bloke, because he used to do a long time ago, he used to do a pool club with me ... Nowt wrong with him at all. The others that came, there was nowt wrong with them. There's a few that's been.' (1/6)

Another member of the same group recalled a student who had focused more on specific matters:

'I remember there was this one that used to come, and she was a lass and she was a nice person to talk to and I remember when she first came she did like a thing on me. You know like an assignment on me. She was asking me questions and that about me ... You see you can talk to them and they'll talk to you and they're nice to get on with.' (1/6)

The group identified why the student nurses spent time on placement at the centre: *'cos they were trying to learn different things, to use what we did to go back to the hospital and do*

things' (1/7). One example of this was when one participant outlined how student nurses at the centre could learn about epilepsy: *'When they realised when people have fits and ... You're always there to make sure he's all right. Even on buses'* (1/9).

6.4.2.1 Comment

This material raised some issues that might be usefully considered by educationalists. It is clear that a variety of models exist ranging from a simple 'bringing on board' model where individuals are recruited to provide personal testimony or witness to placements where nurses 'practise' the development of their theoretical knowledge to competent practice-based skills. Service users appeared to have some choice about whether or not they were involved in educational initiatives, but not whether their 'services', such as their own homes, were used to provide learning opportunities. None reported being asked to consent to this nor having input into the choice of student or in assessment. Users of mental health services and people with physical disabilities have been at the forefront of developments in this area.

Our research revealed that learning disabled people in the areas we studied did not appear to be collaborating with other disabled people in initiatives around disability awareness training or disability rights. Despite being in community settings, they were identified as resources for nurses working in the field of learning disability or other similar practitioners. To an extent these developments may well be led by service users themselves rather than educationalists. The growth of self-advocacy among people with learning disabilities may be the means by which increasing links with the broad disability movement may develop. Educationalists, however, may wish to consider how they can avoid placing pressure on advocacy groups to be the sole opportunity for professionals in training to engage with service users. This may result in a partial view and may restrict advocacy groups from developing their own agendas.

6.4.3 Family perspectives

6.4.3.1 Knowledge and perceptions

Participants had varying knowledge of the education received by learning disability nurses. Some were well informed. For example, one considered: *'Presumably they have to go through the traditional programme for the nursing diploma or whatever and then go on from there'* (7/4), and that this would be accompanied by practical experience: *'With a sort of "hands on", I would imagine'* (7/4). Another participant thought the status and length of training would be similar to that of teachers, with acquisition of a first degree followed by a programme of study involving perhaps child development or spending time with a qualified practitioner (7/4). As this participant envisaged it, the training would be *'a bit of both practical and theoretical'* (7/4). In another interview with the mother of a man with learning disabilities living in the parental home, the respondent admitted she had *'not thought about'* the training of learning disability nurses (3/6), but supposed they followed general nursing programmes and then specialised in learning disability.

Although few participants were able to comment on this area, related themes of training and education arose in the earlier discussions. One participant, for example, felt that a particular learning disability nurse had not had much experience with children and so was not able to assist with puberty issues relating to her daughter (5/18): *'It wasn't anything I could put my finger on and say he was stood back, he was like this, it was just ... He was uncomfortable with it'*. In another group one participant considered with regret that general nurses did not now have any specific training in learning disability: *'So that's got to be their own specific interest ... It's amazing when it works well but I guess we all accept it when it doesn't.'* (2/17)

6.4.3.2 Involvement in education

Among the family members interviewed, a number had been involved in professional training and education. One did not find this exceptional: *'We've been there, done that'* (2/20).

A carers' group ran one-and-a-half-day workshops for the SSD and for social work, psychology and Project 2000 programmes at the local educational institution. In this role the family members provided a testament of or witness to their experiences: *'I'm, if you like, your tame carer, I don't bite your head off... and I can go in and tell you what it feels like and I can be honest because for me it's safe to do that'* (2/20). In this group, one participant outlined how she had been stopped in the street by a nurse who had been motivated by one of her sessions:

> *'I was driving around one day and he said "stop the car, get out" and I thought "hell, what now?" and he said "you came down to university, brilliant day, you made me look at the way I work, every day I work". [Then I] got in the car and drove off again...'* (2/21)

Another strong reaction was recalled by parents from a group where participants had been involved in teaching 'at the hospital' for student nurses on the paediatric branch:

> *'It was more to do when she [daughter] was first diagnosed and how you were told and what support you got at that point and you could see the horror when you actually told your story. They all said "I can't believe it, I would have said that", and I don't think they realised ...'* (5/17)

However, one participant felt that one particular occasion of providing an account of personal experience to members of a social work team had been very difficult:

> *'I think after my past experience I vowed I'd never do another one. It was horrendous. I just felt to be attacked by everybody. It was the worst group I've ever been with. And the lady that was with me apologised and said she couldn't understand the group being so aggressive. They were really aggressive.'* (5/15)

In contrast, another participant, when outlining her experience to direct care staff, felt it had been highly relevant:

> *'Very valuable. From the nurses, particularly the nurses who are working with people in their own homes ... and small group homes. When I've talked about my experiences, of the problems I've had, bringing my daughter up, then they've said, we look after a lady that does exactly the same as yours and now we understand why. And I think in that case it's been extremely useful.'* (5/15)

From another group came an account of being involved in teaching to an unspecified set of students some time previously: *'Years ago, when Makaton was first introduced I went on a programme and was asked to speak to other people about what it was like to be a parent'* (4/5). However this experience was unique in this group and in another interview the participants had also not been personally involved in training (3/6).

Finally, participants were asked about any possible involvement in the planning of curricula or programme design to see if there was evidence of a broader form of influence and on-going involvement. One group indicated that their input into teaching had evolved: *'We actually got into doing the curriculum basically and altering it'* (2/21). For another their involvement was in terms of a programme that was *'already set up and running'* (5/17).

6.4.3.3 Comment

As we have observed earlier, families have been concerned that nurses should be well trained, and many were willing to offer their own experiences to validate theoretical teaching. Such developments confirm the notion that carers have expertise. This knowledge is increasingly seen as applicable to a wide variety of relationships and systems rather than being expertise solely in respect of one individual family member.

Families who had been involved in educational initiatives generally reported on the experience positively. A number of points are relevant to educationalists in respect of valuing and supporting carers' involvement in education (see Manthorpe, 2000). These include practical arrangements and opportunities for feedback and support.

The families interviewed in this research did not report significant involvement with carers' services generally. It may be that programmes of training for learning disability nurses not surprisingly turn to parents of people with learning disabilities to provide carers' perspectives. This may benefit from a broader approach. Carers have much in common but also important differences. In order to avoid a narrow representation programme staff may wish to encourage carers who have not traditionally been involved in educational provision. Similarly those carers we interviewed had all been involved in education by 'talking to' groups of students. Such a 'performance' may appeal to some individuals more than others. It would be useful to consider additional ways in which carers could participate and to share information about such initiatives and their evaluation.

6.5 Summary and comment

The primary consumers of nurse education – current and future nurses – considered there were serious limitations to current nurse education. While nurses felt that their own education left them with deficits in skills and management ability, they felt that changes in the curriculum had improved nurses' knowledge but reduced their skills and therefore students were not as well prepared for practice as their predecessors.

Some students felt that some aspects of education had improved – degree and joint social work nursing programme students felt able to exploit opportunities not available to their predecessors. However, in many ways current students agreed with their predecessors. While they had an opportunity to develop a sound understanding of and appropriate skills to care for people with learning disabilities, their learning opportunities were limited by the CFP, practical problems in the branch programme and the limitations of practice placements. As a result they did not feel fully prepared for practice and identified deficits in clinical skills, limitations in their ability to respond to health needs and communicate with people with learning disabilities and lack of preparation for managing services and providing leadership.

The indirect users of nurse education – employers, users and families – also identified limitations in current education. Employers clearly were not confident that pre-registration programmes were providing fully competent practitioners. They did not feel involved in the design and delivery of programmes and felt they had to fund top-up education in the form of induction training, mentorship or even additional post-registration programmes. Users and families were also aware of limitations. They appeared willing to participate in nurse education, but while some had been involved, their involvement in the design and delivery of programmes seemed to be rather random and they could and should be involved more systematically.

7.1 The aims and methodology of the study

7.1.1 Aims of the project

Our research was commissioned to evaluate the educational preparation of learning disability nurses to provide care and support for individuals with learning disabilities within the context of multidisciplinary care. We evaluated the ways in which educational preparation contributed to the development of learning disability nurses' competence and the effectiveness of their practice. The study had two interrelated aims:

- analyse the discrete role of the learning disability nurse within the multiprofessional and multi-agency team in a range of care settings
- assess the effectiveness of educational outcomes in professional practice in relationship to the perceived needs of service users and carers and the roles and activities of nurses within multiprofessional, multi-agency teams.

We evaluated the quality of educational preparation using a fitness for purpose framework. The first part of our study examined the current purpose of learning disability nursing describing the development, nature and range of contemporary learning disability nursing practice. This part examined:

- the roles of learning disability nurses in relationship to service users and informal carers within the context of multiprofessional and multi-agency work
- the skills and types of competencies which learning disability nurses need so that they can effectively perform this range of roles.

The second part examined the extent to which current educational provision prepared learning disability nurses for this range of roles and associated competencies:

- the aims and structure of current educational provision
- the ways in which current educational provision prepared learning disability nurses for supporting individuals in the community
- the ways in which current educational provision prepared learning disability nurses to make a contribution to 'seamless' multidisciplinary and multi-agency care.

7.1.2 Methods

Our research was designed to evaluate the ways in which current education prepared nurses to undertake the roles of learning disability nurses. Since both policy and practice in this area has changed radically, it is not possible to use objective or gold standards as a basis for evaluation or, given the importance of user and carer perspectives, is it appropriate to rely on professional standards. Therefore we used a 'fitness-for-purpose' framework for our evaluation, not only because it underpinned the subject review methodology used by the QAA and the Board to evaluate the overall provision of nurse education, but also because it enabled us to explore the nature of current learning disability nurse practice and evaluate the extent to which educational provision prepared nurses for this. Our case study of the educational preparation had two components, a study of 'purpose' in terms of current practice and a study of 'fitness', in terms of current educational provision and the extent to which it prepared students for current practice. We used a case study design as it enabled us to use a combination of methods to triangulate data and to combine quantitative data with qualitative data.

The use of case studies is not without problems. A case study design depends on a clear and uncontested definition of the case to form the basis of the study. While some social

phenomena such as organisations have clear and definable boundaries, others, such as communities or areas of nurse education do not. In such circumstances there is a degree of arbitrariness and pragmatism in the definition of the case. We defined our case as the current process of education for learning disability nurses in England.

7.1.3 Examining the purpose of nurse education

Since nurse education is intended to prepare nurses for practice, the first part of the research concentrated primarily on the nature of current practice, though it also included some insights into the nature of educational preparation. We used three sources: a questionnaire survey to provide a comprehensive profile of current learning disability nurses and the nature of their activities; observation of and interviews with nurses working in a variety of teams to provide insight into the nature and variety of current practice; and focus groups with users and carers to access their experiences and expectations of learning disability nurses.

The questionnaire was distributed to a 10% random sample of nurses (1,864) on the learning disability Parts of the Professional Register. A total of 756 (41.9%) questionnaires were returned. It is difficult to see how this response rate could be improved. One way of improving response rates is to establish personal contact between the research team and respondents; however, given the UKCC specification that there should be no direct contact between the research team and potential respondents this was not possible. Since we did not rely on the survey as the sole source of data, the sample was of sufficient size and scope to generate valuable data on the nature of current practice and assessments of nurse education.

The questionnaire survey was complemented by observation of nurses in practice. These observations were designed to explore in more detail the current role and practices of learning disability nurses, their roles in multidisciplinary teams and the effectiveness of educational preparation. The multidisciplinary teams were selected to represent different types of team and areas of practice. Ten teams were included in the study, and the team spent at least five days with each team. The pattern of data collection was the same for each day. The researchers interviewed the learning disability nurses both at the beginning and at end of the day they spent under observation, and spent the day observing the nurses in practice. Since formal observations may distort the pattern of activities, nurses were invited to participate in self-observation by completing diaries for a 10-day period following the observation. Out of 24 nurses observed in practice, 16 returned diaries. Members of the multidisciplinary team were also interviewed in order to explore their perceptions of the role of the team, their own role and that of the nurse member(s). These observations enable the research team to build up a picture of the different roles that learning disability nurses performed, and therefore were a key element in defining the purpose of education.

While there is a strong commitment within the DoH and the NHS to accessing user and carer views on services and ensuring services meet their perceived needs (DoH, 2000, para 10.1), in practice much research is done from a service or provider perspective. For example, a recent scoping exercise for a major NHS programme of research noted that *'While many surveys have sought the views of patients these have almost exclusively taken a professional perspective of care. Little is known about patients priorities for continuity of care'* (Freeman et al., 2001: 3). We were determined to provide a voice for users and carers, and therefore focus groups with them were an important part of our research, providing a way of exploring users' and carers' perspectives of the role of professionals and the adequacy of educational preparation. Eight focus groups were held in the latter half of 1999. Three were composed of people with learning disabilities, one was made up of seven family members – two of whom had learning disabilities, and four were composed of family members mostly parents. The groups came from a range of urban and rural locations throughout England and were a mix of voluntary support groups or established user groups meeting within day service settings. The focus groups addressed participants' perceptions of the role of learning disability nurses and their participation in their education.

7.1.4 Evaluating educational preparation

The second part of the study was designed to evaluate the educational preparation of learning disability nurses for their contribution to the multiprofessional, multi-agency team. There were two main components to this.

A survey was undertaken of all available programme documentation held at the Board's regional offices, with the exception of second to first level conversion programmes. A total of 163 programmes for learning disability nurses were analysed from 49 institutions. The programmes were systematically analysed using a number of themes which included: aims and objectives, learning outcomes, teaching methods, assessment methods, evidence of shared learning, values taught, teaching and learning philosophy, user/carer involvement in programme design and delivery, preparation for multiprofessional, multi-agency work, organisation and assessment of placements. This provided valuable insight into the intentions of the educational institutions when they had sought Board approval.

Twelve programmes were chosen for more detailed analysis. They were selected to represent both pre- and post-registration learning disability nursing programmes, different types of programmes and different geographical locations. Where possible programmes were also selected on the basis of distinguishing features – such as distinctive organisation, linkage between health and social care and special elements to prepare nurses for multiprofessional, multi-agency teamwork. To build up a more comprehensive picture of current nurse education we visited the institutions providing the programmes, interviewed programme leaders and conducted focus groups with students. Later, we approached the main employers of students from the programmes to arrange interviews with them so that we could gather a rounded view of the current system of nurse education. We invited students to act as observers of the learning process by completing a diary recording their observations, and received eight diaries. This variety of data enabled us to build up a picture of how the curriculum was delivered and whether the participants felt that the programmes achieved their prime objectives of developing or enhancing the competencies of learning disability nurses and preparing them for practice.

7.1.5 Comment

We found that the case study design was a robust and flexible way of examining the nature of current educational preparation of learning disability nurses and the ways in which it prepared them for current practice. The main strength of this approach is that it facilitates the triangulation of data so that the sum is greater than the parts. The findings come from and are supported by a combination of methods generating complementary data.

7.2 Development of the role of the learning disability nurse

We provided a context for our study exploring the development of services for people with a learning disability and the associated development of learning disability nursing. We used two main sources to achieve this. Our account of developments in the earlier periods was based on a variety of historical sources. However, for the final period we could supplement these sources with primary data from our own study, especially data from our survey of learning disability nurses. Many of these nurses trained in the 1970s and 1980s.

We examined three periods in which significant service developments occurred: the 1850s to the 1920s; the 1950s to the 1960s; and the 1970s to 2000.

7.2.1 Development of services for people with learning disabilities

In the mid 19th century there was an optimistic attitude amongst some professionals that children and adults with a learning disability could be educated, and small specialist institutions were established to provide education and training. Their results were not promising

and by the end of the century people with learning disabilities had been caught up in and become victims of a wider eugenic debate. Eugenic research and propaganda presented people with learning disabilities as ineducable and as a threat, and services responded accordingly, putting them in large institutions away from the public eye. Specialist nursing developed out of attendants and keepers in response to a number of factors. Although they developed proper training and their own register, these nurses were not fully accepted within the nursing profession, as they were not seen as carers of the sick.

Following the Second World War there was a change in both attitudes and policy. Institutions were no longer seen as appropriate for people with learning disabilities, partly as a result of renewed optimism regarding their potential and capabilities. Researchers and policy-makers identified the need for radical changes in services and laid the foundations of today's community care policies and a reorientation from the threat to society which had underpinned eugenic propaganda to the needs and interests of people with learning disabilities. Service developments were increasingly based on their educational and social needs, as opposed to their medical and nursing needs, which had formed the basis of care in the institutions. Families' contributions to care were recognised, and policy-makers emphasised or rediscovered family-based or 'homelike' care. This period was a time of uncertainty and insecurity for nurses. The new policies and changes in the provision of services meant that they were in danger of being left without a clear role as services began to move into to the more varied setting of the community in which other occupations could play a key role.

The 1970s consolidated the developments of the post-war period. The development of explicit ideologies of care such as normalisation provided a framework for the development of patterns of care based on the principle that people with learning disabilities have a right to valued lifestyles as integrated, empowered and included members of the community. Since the 1970s, policies have promoted the move away from institutions for all people with learning disabilities with the exception of forensic services for individuals who are perceived as dangerous. Many services have been designed to maximise independence, to allow individuals to make their own decisions and choices and to include them more widely in the community. Services are now provided by a number of agencies offering greater choice and opportunities for people with learning disabilities, though they continue to have resource problems and some are plainly unacceptable in quality. Learning disability nursing has established a clearer role and position within the new pattern of services. The DoH has acknowledged that learning disability nurses have an important role in meeting the needs and expectations of service users and their families. Recent changes in policy and service provision have led to increased demands being placed on learning disability nurses. They have been expected to develop new roles, skills and methods of working.

7.2.2 Perceptions of the impacts of the changes: nurses' views

Learning disability nurses have had a major reconceptualisation and restructuring of their field of practice in recent years. There have been changes in all areas of their profession including their value base, location of practice, employers and management structures, and in the skills and knowledge expected of them. Our survey respondents recognised that a change in terminology underpinned a major shift in values and systems of care. Several distanced themselves from 'old fashioned' terminology, for example, mental subnormality or mental handicap to emphasise the change in values. They both recognised and endorsed the major changes in values and the importance of taking account of what users wanted – people with learning disabilities had more choice, rights, dignity and privacy.

Most respondents felt they had moved from the relative security of institutional care into more varied and challenging settings in the community. They believed they had adapted to such new environments and methods of working in the face of difficulties which surround the availability of resources. They presented a picture of sustained struggle to gain recognition of the value of their skills.

Nurses identified two perhaps contradictory trends: a greater emphasis on the learning disability nurse as a manager and at the same time a greater diversity of roles performed by learning disability nurses providing specialist support for people with learning disabilities and their families. Many respondents felt that the amount of user contact they had was being eroded by the imposition of managerial and leadership responsibilities and ever-increasing amounts of paperwork. Specialising in areas such as behavioural therapy or community nursing were ways of maintaining direct contact with users, but not all respondents wished to focus on just one area of practice.

7.2.3 Comment

The last 100 and, perhaps more importantly, the past 30 years have witnessed significant changes in the provision of services for people with learning disabilities. Services have usually developed in response to policies that, in turn, were influenced by the prevailing attitudes and prejudices of the time. These changes are now accepted, indeed seem to be taken for granted, and for most nurses they appear to represent progress and modernisation of both services and their own role.

7.3 The current roles of learning disability nurses

We developed our analysis of learning disability nurses by examining their current roles. We started by developing a conceptual framework using current literature on nurses' roles and associated competence. We then considered how the nurses defined their roles using evidence from our questionnaire survey. Finally we considered the nature of current practice using observational and interview data from our fieldwork.

7.3.1 Defining competence

Professionals, such as learning disability nurses, play a key role in the delivery of health and welfare services in contemporary society, and their knowledge and skills underpin the welfare state. Advanced professional training assures governments and citizens that some professionals have developed skills appropriate for more specialist practice and/or that each professional is appropriately updating his or her basic competence.

However, as with many key concepts in health and welfare, both the definition and nature of competence are contested. Competence is usually defined in terms of the task that needs to be undertaken and the 'competent practitioner' has skills that are appropriate and sufficient for the tasks within his or her scope of practice. The competent professional is expected to have not only appropriate skills but also the theoretical knowledge which enables him or her to understand whether the application of a particular skill is appropriate and the likely effects of its application. However, the competence of modern professionals includes not only appropriate skills and supporting knowledge but also appropriate values. Rule 18A of the Nurses, Midwives and Health Visitors Approval Order (1989) provides a legal framework for defining and assuring nurses' competence. However it is a general framework for all nurses and therefore our study identified the specific competencies required by learning disability nurses by examining their roles in different types of practice.

7.3.2 Learning disability nurses and their changing role

The findings from our survey provide more evidence for the major changes in patterns of employment and work that have taken place in the last 30 years. The majority of nurses who qualified more than 10 years ago had initially been employed in hospitals on traditional hospital nursing grades. Major changes in the configuration of services have meant that while the majority of respondents continued to be employed by the NHS, only a minority now work within hospitals or specialist units and retain traditional hospital titles. Most were working in community settings providing care and support for people with learning disabilities mainly living in residential units. A minority did not view their work in terms of nursing.

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This change in the nature of employment has had a major impact on the nature of work and the required skills and knowledge to practise learning disability nursing. While the provision of care and support remains a major component of learning disability nurses' work, our respondents considered management, liaison and education as the most important elements. Consequently in their everyday work they needed to develop and use skills in these areas as well as personal care skills. However, when asked about underpinning knowledge and values, respondents tended to see these in traditional caring terms. Thus they emphasised the importance of knowledge about people with learning disabilities and of traditional vocational values. These were unexpected findings. Within the field of learning disability there has been a development of a clear and powerful value base for the provision of care and support especially through the principles of normalisation or social role valorisation. Not only has this been promoted by pressure groups such as Values into Action, but it has also underpinned models of care such as Ordinary Life, which have been incorporated within current policy and practice. It is not clear why our respondents made no explicit reference to these types of value statements.

7.3.3 Evidence from multidisciplinary teams

Our interviews with member of multidisciplinary teams indicated that nurses and other team members appeared willing and able to acknowledge each other's standing and skill. While they acknowledged that there was some overlap between the role of the nurse and that of other members of the multidisciplinary team, there was also awareness of the distinctive contribution of the nurses, especially in holistic care. Nurses saw their role in terms of providing direct care, integrating the team and providing specialist knowledge. They combined knowledge and understanding of the needs of people with learning disabilities and knowledge of the needs and care of specific individuals. Thus learning disability nurses were ideally placed to co-ordinate the more specialist contribution of other team members and provided overall management of care for individual clients. However, nurses were less willing to acknowledge a function which other team members ascribed to them, that of managing services.

Nurses received less respect from unqualified workers, who were unwilling or unable to recognise and acknowledge learning disability nurses' distinctive contribution. Unqualified workers tended to see their role and that of learning disability nurses as interchangeable, and argued that where nurses did have distinctive roles these were in either restricted technical areas such as medication or in management skills where experience and personality were more important than professional training.

Nurses clearly felt that they had a contribution in terms of skills that they felt to be unique to their profession and therefore could not be carried out by anyone else. They referred to skills such as assessment and report-writing, management of behavioural difficulties, and building therapeutic relationships with people with learning disabilities.

As well as asking nurses and other members of the multidisciplinary team about the role of nurses, we also observed 24 nurses from 10 teams in a variety of settings and 16 nurses maintained self-report diaries. Our observation of nurses indicated that there they undertook a variety of roles requiring different skills and competencies. Observation of nurses and analyses of their diaries does indicate that some, especially relatively junior nurses in residential settings are predominantly 'carers' and spend the majority of their time providing direct care. In this role nurses needed the skills and knowledge to plan and deliver care to a variety of users.

This type of role was by no means universal. As nurses progressed in their careers their roles changed, they moved into more managerial or specialist roles. This change in roles was reflected in changing patterns of activity and this was clearest for senior nurses in managerial roles. It was difficult to identify any direct care in their daily work, which was dominated by management and administration. They spent most of their time doing paperwork, answering the phone or in meetings. It was clear from interviews with nurses who had specialised in this aspect of nursing that they did not value the managerial work but valued direct work with service users.

The alternative role for senior nurses was in specialist therapeutic areas where they acted as a specialist adviser or consultant. While there was some contact with users the advice provided was often to staff or informal carers. Nurses performing this role needed specialist knowledge, for example of challenging behaviour, the ability to assess needs in this area and the skill to provide advice and guidance and in some cases to deliver specialist therapies. While this role was valued, there were some difficulties. Since specialists were essentially performing a support role they had to rely on others to use their service effectively, and a high proportion of their time was spent travelling between locations.

The apparent emphasis on the care role, which was evident in interviews with nurses, can be explained by a number of factors. Nurses were attracted to the profession because they wanted to care for users and it was clear from the diaries that they valued this aspect of their work highly. While many had moved into managerial posts, they saw this as a necessary price of promotion and wished to maintain their identity as nurses who provided care. The emphasis on the caring component of nursing can also be seen as defensive. While other professional members of the multidisciplinary team clearly recognised and valued both nurses' caring and managerial skills, unqualified workers did not. It appeared that nurses responded to this pressure from below by emphasising the vocational and caring component of their role.

7.3.4 Comment

These findings indicate the importance of using multiple sources of data to examine the roles of nurses. If we had relied solely on interviews with nurses, we would have got an impression that the primary role of nurses was as providers of direct user care. However the other sources indicated that while some nurses, especially relatively junior nurses in residential settings were predominantly 'carers' and spent the majority of their time providing care, this was by no means universal. As nurses progressed in their careers so their roles changed. They moved into more specialist or managerial roles; this was reflected in a changing pattern of activities. The change was clearest for senior nurses in managerial roles. It was difficult to identify any direct care in their daily work, which was dominated by management and administration. Specialist nurses had a more varied workload, providing support to users in a variety of settings; travelling between these settings was a major feature of their working day. While specialist nurses did provide direct services to users, more often their specialist input was targeted at one remove, to individuals who provided direct care and support for users, their families or residential staff.

7.4 Users and carers: perceptions of and role in nurse education and practice

In our work with multidisciplinary teams we had the opportunity to observe the ways in which nurses interacted with both users and carers. However it was not possible to examine users' and carers' perspectives of the role of professionals and the adequacy of educational preparation. We used focus group methods to investigate these perceptions since these are an established way of collecting experiences and opinions in a non-threatening and efficient manner. We also used our analysis of programme documentation and interviews with programme lecturers and students to explore the current involvement of users and carers in curriculum design and delivery.

7.4.1 User and carer perspectives

Changes in attitudes to both users and their families have meant that interest in their views has grown. While the early development of services was characterised by suspicion between providers, users and families, increasingly the emphasis is on partnership, with opportunities for user-led services emerging in community care. This change is marked by terminology – patients have become clients and increasingly 'service users'. In parallel with increased emphasis on developing partnership with users of services and family members or

carers over the delivery of treatment, support and services, has been growing attention to the potential for user and carer participation in professional learning. Within social work, the professional validating body has sponsored a series of publications outlining models of user engagement in social work education.

7.4.2 User perspectives

Users who participated in our focus groups had contact with and were aware of the learning disability nurses. They tended to see the distinctive role of learning disability nurses in functional or medical terms, such as taking blood pressures or giving medications. Several saw the nurse as providing help both routinely and during a crisis. Users particularly valued the personal relationship they had with their learning disability nurse, and several referred to their nurse as a friend and clearly trusted them. Users differentiated learning disability nurses from other nurses in terms of activities, appearance and location. Learning disability nurses provided general help, they were friendly and provided help in the community. Other nurses provided technical treatments, wore uniforms and worked in hospitals.

Our interviews indicated that service users valued practitioners who had a human face, rather than assuming technocratic or bureaucratic identities. In terms of quality indicators their perceptions were similar to those advocated by a group of parents who were interviewed about short-term care for their disabled children. Russell (1996) summarised these as:

- being local and accessible
- providing good care – not medicalised but not ignoring special needs
- available on demand
- being integrated with other support.

7.4.3 Families' perceptions

The focus groups provided some evidence that families saw themselves as having needs different from those of people with learning disabilities, confirming a growing appreciation that user and carer perspectives may legitimately be distinguished. Many participants who were parents had experience or contact with learning disability nurses. For some this extended to years of accumulated experience; others had brief or intermittent contact.

Most felt that learning disability nurses possessed particular expertise in the care of people with learning disabilities, whether this was medical, epilepsy and medication, or helping with behavioural problems. Some also acknowledged that they were well informed about other matters such as benefits. In essence, learning disability nurses were specialists who could help family members, particularly parents who regarded themselves as very much the experts. In addition to the experience acquired by learning disability nurses in working with people with learning disabilities, a number of parents spoke of learning disability nurses as possessing skills in working with parents or families. These ranged from liaison or co-ordinating skills to direct quasi-therapeutic help or support for carers at an emotional level. Personal contact was important and it was seen as promoting feelings of trust and security. In contrast to social workers, parents felt that learning disability nurses were not so likely to be judgemental or to invoke the spectre of child protection.

Just as some users saw learning disability nursing in personal rather than just technical or activity terms, so did family members. However, while users tended to see these personal aspects in terms of friendship, family members saw it in terms of vocation. The choice and interest of the learning disability nurse was contrasted to other nurses' ignorance at times and society's indifference or prejudice. While families did recognise that some other nurses had the knowledge and personal skills to understand and meet the needs of people with learning disabilities they felt that this was exceptional.

These carers presented a picture of a complex organisational world in which organisations, terminology, professionals and services were subject to frequent change. This affected whether they recognised learning disability nurses among the many professionals they had encountered over the years. Their difficulties in conceptualising the role of learning disability nurses reflect the limited contact of such nurses with carers overall.

7.4.4 Opportunities for user and family participation in education

Given the importance attached to developing partnership with users of services and family members or carers over the delivery of treatment, support and services, there has been growing attention to the potential for user and carer participation in professional learning. We examined programme documents and interviewed lecturers and students to examine the ways in which users and their families were involved in the development and delivery of programmes.

In all the documents analysed, users were the prime focus and main concern. Programme designers clearly saw their programmes as ensuring that future nurses would be aware of and could meet the needs of carers. This was particularly evident in pre-registration programmes. Some documentation indicated that users had been involved in the design process and some also included a statement that there was intention to involve users in the delivery of the curriculum.

While users formed the central focus of programmes, the interests of families were less frequently and explicitly identified. It appears that in some programmes their interests were not separated from those of service users. When families and other informal carers were identified they tended to be grouped with either users or with professional carers in terms of participation in programme development and delivery.

Lecturers did see the aims of their programmes in terms of meeting the needs of users and supporting carers, and were committed in principle to involving users and families in the design and delivery of the curriculum. However, in practice most acknowledged that the participation was limited and that they were not the main drivers in the development of the programme, nor did they play a major role in the delivery of programmes. It was clear that they saw this role as limited and secondary. While lecturers were anxious that user and family involvement should not be tokenistic, it appears that both the form, in some cases using voluntary agencies as surrogates, and limited extent made it so. We did not feel that the argument that students would get an opportunity for 'real' contact with users and families when they did their practice placements was an adequate response.

However, students in the focus groups did not even identify tokenistic participation in their education. In our interviews with current students, none identified any involvement of people with learning disabilities or carers in the classroom context. Only one group referred to them commenting that while no users or carers were involved they *'should be though. It needs to be changed'*.

7.4.5 Users' and carers' perception of education

In our focus groups we were able to access both users' and families' perceptions of and participation in services.

7.4.5.1 User perspectives

Participants in the focus groups composed of people with learning disabilities were aware of nurse education through the contact they had had with student nurses encountered within care or service facilities.

Two groups were actively involved in nurse education, the self-advocacy group appeared to be a focus for education and the day centre appeared to provide a placement for nurses, while it appeared that participants in the third group had experienced occasional placements in their day centre.

While all participants seemed willing to be involved in nurse education, it appeared they did not feel they had control over the process, nor were they equal partners. The education took place mainly in their care settings. While they appeared to have some choice about whether or not to be involved in educational initiatives they did not appear to have any over the use of their 'services', which could include their own homes, as the location for student learning. None reported being asked to consent to this, nor to having input into the choice of student or in assessment.

It appears that while users of mental health services and people with physical disabilities have been actively involved as partners in education, the users in our study were still being treated as the passive source of knowledge and a medium for the development of student skills and competence. It is important that users are treated as active participants and are given a full and active role.

7.4.5.2 Family perspectives

The family members who participated in our focus groups had varying knowledge of the education received by learning disability nurses. Among those interviewed, a number had experience of being involved in professional training and education, though this was often in a personal capacity rather than as part of an organised 'carer' group, as most had limited involvement with formal carers' groups. They tended to see their involvement as a one-off rather than as part of an overall strategy that provided them with opportunity to develop their skills and expertise.

Parents were able to provide a testament of or witness to their experiences. Although some had 'horror stories' of involvement, most found the experience positive – though they would have welcomed more feedback on their contribution. Involvement in curriculum development appeared to be limited and when it occurred seemed to be a development of involvement in the delivery of the curriculum.

Families were concerned that nurses should be well trained, and many were willing to offer their own experiences to provide practical illustrations of theoretical teaching. Such involvement was seen as a confirmation and legitimation of their expertise. This knowledge is increasingly seen as applicable to a wide variety of relationships and systems, rather than being expertise solely in respect of one individual family member.

While most parents seemed to welcome the opportunity to participate in education, it was not clear that they were involved as partners in the enterprise. If a partnership is to develop, it is clearly important to find ways to involve parents in curriculum design and development. Furthermore it is also important to consider how and in what ways parents can benefit from their participation in the educational process.

7.4.6 Comment

Those users and carers who clearly identified learning disability nurses were positive about their role and competence. In particular they valued their expertise in relation to people with learning disabilities and their personal qualities. People with learning disabilities saw these personal qualities in terms of friendship while their parents tended to see them in vocational terms.

However, it should be a cause of concern that some parents could not clearly identify and differentiate the unique role of learning disability nurses. Parents reported some difficulties in accessing services for themselves or the cared-for person. While much research and good practice continues to argue for 'key' co-ordinators to help families through the service maze, our research indicates that many negotiate their own pathways. Finding a helpful, accessible professional, of whatever kind, appears to be some families' response to the deficit on 'key' workers: in a sense they try to create their own. Parents appeared to place high value on practitioners' abilities to forge relationships with families, and this paralleled the views of people with learning disabilities.

Users and parents recognised the importance of professional and nurse education and appeared willing to participate. Programme documentation indicated a commitment to involving users and carers. However, the reality does not currently match the rhetoric. Lecturers expressed concerns that user and carer participation was tokenistic. While interviews with users and cares indicated that most users and some carers had been involved, it appeared that this did not amount to equal participation. Users had little control over the process, while most carers were either not involved or only sporadically. It is important that progress is made in this area so that there is a closer alignment between the aspirations evident in programme documentation and reality.

7.5 The educational curriculum

Traditionally, nurse training was designed to provide nurses with appropriate practical skills and socialise them into a strong vocationally-orientated culture. In this form of education, the learner was seen as passive, an empty vessel to be filled with appropriate skills and values. The rethinking of nurse education, which started with the development of nursing degree programmes in the 1960s, changed both the content of the nursing curriculum and the ways in which it is delivered.

The development of nursing degrees within the framework of higher education placed increased emphasis on supplementing practical skills with appropriate theoretical knowledge. There was also a greater recognition of the role students could and should play in the learning process, and that pre-registration programmes were only part of a process of lifelong learning in which nurses continued to develop their skills as knowledge developed and their careers developed. The development of a theoretical foundation for nursing practice was associated with awareness of a theory-practice gap.

Our analysis of programme documentation, and interviews with lecturers and students provided a clear picture of the nature of educational curriculum. Programmes aimed to produce competent practitioners who were committed to the interests of people with learning disabilities and had the appropriate knowledge to provide care that enhances their autonomy.

7.5.1 Evidence from programme documentation

While all the programmes studied declared their aim as developing the competencies of nurses, there was a basic division between pre-registration programmes and post-registration advanced practitioner or specialist programmes. Pre-registration programmes aimed to develop a basic, all-round, competent learning disability nurse, who was fit for practice, whereas post-registration programmes aimed to enhance pre-existing competencies in specific ways. Joint nursing and social work programmes aimed to educate the competent 'hybrid' practitioner.

Programmes had a broad definition of competence. They did not restrict it to the use of skills to provide care for a range of users, but were concerned that these skills should be used reflectively and that students should have the ability to continue their professional development when they had completed their programme. Most specified not only that the practitioner should be competent or 'fit for purpose' but that he or she should be 'reflective'. While technical skills were important, the reflective practitioner should be able to develop his or her practice through critical analysis and the appropriate use of evidence. Programmes wanted nurses to have the capacity to develop and keep up to date. Thus they aimed to create a commitment to lifelong learning.

The designers of learning disability programmes clearly attached importance to their value and ethical base. There was a strong emphasis, especially in pre-registration and specialist practitioner programmes, on the value base of all student learning. Specialised programmes tend to be seen primarily in technical terms and therefore were justified in utilitarian terms, that is the development of knowledge and skills to benefit users. Post-registration programmes, such as those dealing with violence and aggression or forensic services generally did not include

clear value statements, and if they did these tended to be brief. Most pre-registration programmes emphasised the rights approach that stressed the human rights of people with learning disability and saw the nurse as a key person in enabling them to exercise those rights especially through participation in decision-making.

In specialised programmes, the main emphasis was on knowledge underpinning specific skills or which could be used to address a specific need. For other programmes, knowledge specification was mainly extensive rather than intensive. The knowledge specification of specialised programmes tended to be limited because they were usually one- or two-module programmes, and the type of knowledge provided was treated as self-evident. Knowledge specification often formed part of the overall aims of the programme.

The pre-registration and specialist practitioner programmes provided more detailed specification of the types of knowledge they were designed to provide. A detailed analysis of 11 pre-registration diploma programmes indicated a specification of 165 areas of knowledge. The two main areas were covered – the knowledge underpinning the provision of care and support, and specialist knowledge providing insight and understanding of the situation of people with learning disabilities, with lesser coverage of the knowledge underpinning the management of care. A more detailed breakdown of the contents of the documents indicated that in each area there were 'essential' topics which were included in nearly all programmes, and 'optional' topics which were only included in a minority of programmes.

All programmes were committed to developing students' nursing skills. The programme generally specified the process, some form of practice placement, and the specific outcomes, though the linkage between these was poorly articulated. Only a minority of programmes linked the description of practice placements with learning and skills outcomes.

The programme documentation provided specifications of the skills which students were expected to have on successful completion and were seen as necessary for effective practice. To identify how programme designers defined the requisite skills of registered nurses we undertook a further analysis of 11 pre-registration diploma programmes that provided the evidence for the knowledge base. These programmes were committed to the development of care skills required to provide care and support for clients, skills to manage services, research skills to support the development of an evidence base and personal skills required for effective care.

7.5.2 Lecturers' view of the educational process

We interviewed lecturers in charge of 12 programmes to examine their perceptions of the aims of their programme and how they saw their programme contributing to learning disability nurses' competence. Within the time available, the lecturers could not provide the level of detail included in the programme documents, but their descriptions of the programmes tallied with those in the documentation.

Lecturers accepted that the main aim of their programme was developing or enhancing learning disability nurses' competence. However, they varied in the ways in which they defined this competence. While most defined it in terms of fitness for practice, two defined it in terms of educational process and acquisition of specific values or special knowledge and skills. Furthermore those who saw competence in terms of fitness for practice also differed in the way they defined purpose. Some saw this in terms of a flexible practitioner who could work in a variety of settings, whereas others emphasised the importance of meeting the service needs specified by particular employers.

Lecturers tended to downplay education as a mechanism of providing knowledge. They did not see the prime function of college or classroom teaching as an end in itself but very much as a means to an end. They saw it as one means of preparing students for practice and therefore as the underpinning for the development of skills.

While lecturers seemed reluctant to talk about the formal teaching, they were happy to talk about the development of skills in practice placements. They clearly saw this as a crucial aspect of the development and/or enhancement of nursing competence. Lecturers emphasised the importance of students developing care skills in their placements. They also expected students to develop management skills, especially in the final placements on pre-registration programmes.

7.5.3 Students' views of education

We conducted focus group interviews with 57 final-year students on 12 programmes. These students accepted that the main aim of their programmes was to develop or enhance their skills as learning disability nurses, and were committed to developing such skills which would improve the situation of people with learning disabilities. While they did not describe the detailed content of their programmes they saw them as providing learning opportunities both in classroom teaching and in practice placements.

A number of the students found difficulties in providing a more detailed description of the overall aims and objectives of their programme. They pointed out that they had been given specific aims and objectives for individual modules, but no aims and objectives for the programme as a whole.

Most students in the focus groups recognised the explicit value base of their programme and especially the importance of normalisation and ordinary living approaches. However, they tended to express their own values in more practical terms, such as helping people with learning disabilities. They expressed their values most clearly in discussions about how and why they chose the programme. Most saw their decision to train as a learning disability nurse as a positive choice. While a number of factors influenced their decisions, the unifying theme was an interest in and commitment to caring for people with learning disabilities. Several students indicated that they had chosen learning disability nursing in preference to other branches of nursing. One student on a pre-registration programme indicated that she had chosen it because of its holistic focus. For many students undertaking nurse education was a way of improving their own status while at the same time helping people with learning disabilities. Indeed they saw these two processes as linked; by developing knowledge and skills they could use their position to help people with learning disabilities.

Students recognised that they were provided with learning opportunities in class and in practice placements. They accepted that formal teaching was designed to develop or improve their nursing skills, and saw classroom teaching as an opportunity to learn specific skills. Students on pre-registration programmes did not discuss in detail the opportunities provided by classroom-based teaching as they felt it was part of the general process of 'becoming a first level nurse'. Students felt that practice placements provided crucial learning opportunities, enabling them to apply the theory they learned in the classroom and giving them an opportunity to build up their competence and confidence as nurses.

7.5.4 Comment

Traditional nurse education was designed to produce nurses with a relatively standard package of practical skills. Contemporary nurse education is more flexible. It is designed to provide students with learning opportunities so that they can develop appropriate skills grounded in theory and evidence. Central to this process is the creative interaction between class teaching and practice experience.

The learning disability programmes surveyed aimed to produce flexible nurses who were not only fit for current practice but had the ability to adjust to changing situation through lifelong learning. The curricula were grounded within a strong commitment to the needs and interests of people with learning disabilities and practice that empowered them. The programmes clearly specified appropriate knowledge including that underpinning care skills, specialist underpinning theory and knowledge of management. They also specified necessary skills

including care skills, personal skills, research skills and personal skills. Analysis of the documentation of 11 pre-registration programmes indicated a common core of knowledge and skills evident in most programmes but considerable variation in terms of optional areas.

Our interviews with lecturers and students were consistent with the evidence from programme content analysis. There was agreement that the learning in placements was crucial for the development of competence in nursing, and that the acquisition of knowledge was very much a means towards an end, the development of a competent nurse.

7.6 Developing skills: perceptions of the learning process

The primary consumers of nurse education are past students who are using their knowledge and skills in their work, and current students who intend to do so in the future. Employers, users and families were indirect consumers as they use the services of qualified nurses. Any limitations of the educational process will have a major impact on them – employers may need to make good limitations with additional training, while users and families may receive inadequate or inappropriate services. The perceptions of primary and secondary consumers were a crucial part of our evaluation.

7.6.1 Current nurses, former students

In our questionnaire survey we asked respondents to evaluate both their own educational preparation and that of current students. Generally they were aware of the limitations of both.

While most respondents were positive about their initial education, they were also able to identify one or more educational deficits which had become apparent within two years of qualification. The major deficits were in administration and management, though respondents also identified deficits in caring skills, skills needed for liaison work and skills needed to educate students.

Many respondents used their own nurse education experience as a baseline for evaluating current provision, and clearly felt their own education had been far superior. While they acknowledged some limitations in their own education, they felt that innovations such as the development of Diploma in Higher Education programmes had not enhanced the quality of education. In particular they felt that students completing such programmes were not adequately prepared for practice. The programmes did not, in their opinion, offer adequate opportunities for students to develop practical skills.

When invited to comment on current education preparation, a minority of respondents felt that they did not know enough about current provision or had no contact with students so could not comment. A minority of those who did respond to this question felt that the training was adequate, and a small minority felt that the balance between theory and practice was good. The remaining respondents were critical. They did not feel that students were adequately prepared for practice, and identified a number of limitations. These included: inadequate placement problems and inadequate preparation for practice, limitations in the development of key skills, and problems with the CFP.

7.6.2 Current students, future nurses

In our focus group interviews with 57 students on 12 programmes, we invited them to comment generally on their experience of the programme and specifically on the whether they felt it prepared them for practice as learning disability nurses.

How students evaluated their education depended on their expectations, especially how they defined the role of the learning disability nurse, and this formed our starting point. Generally the participants did not find it easy to specify the role of the learning disability nurse

– some either used tautological definitions or suggested the role was context-specific. When prompted, most groups were able to provide a more detailed specification. Most groups agreed that an important element of the learning disability nurse's role was acting as an advocate for people with learning disabilities and enabling them to make choices about their lives. All students acknowledged the 'broad specification' of the learning disability nurse's role and the importance of providing care and support for people with learning disabilities, especially providing health care. For many, health care encompassed all aspects of care. While students felt that the main roles of learning disability nurses were to act as advocates for people with learning disabilities and provide them with care, they acknowledged that to do this nurses needed to be able to manage services and to provide leadership, especially for other care staff.

Generally, the pre-registration students felt that their 'learning disability' education only started when they entered the branch programme, which they felt offered them real learning opportunities. Most commented positively on the learning opportunities provided in their branch and post-registration programmes. Students' main criticism of branch and post-registration programmes related to practical problems that prevented them learning, especially the perceived disorganisation of many programmes. We were given many examples of disorganisation.

While students acknowledged the learning opportunities offered in educational institutions, indeed students on degree programmes felt able to exploit a wide range of learning opportunities, most felt that their real learning took place in practice placements. When they were asked to identify the things they liked most about the programme, practice placements were the most frequently cited response. Students enjoyed being out in the workplace, where they were able to put what they learned in the classroom into practice. Students on joint nursing and social work programmes felt that they benefited from placements in both health and social care settings. Students particularly valued placements in whose selection they had been involved. For example, post-registration students who were able to select their own placements were especially positive. As with learning in class, students felt that practical problems often prevented them making full use of the learning opportunities provided in practice. They felt that many placements were too short and inadequately prepared, there was a lack of choice and variety and they were not adequately prepared for or supported in practice.

Pre-registration students were invited to comment on whether they felt prepared to practice at the end of their programme. Only one said that she was confident enough and ready to take on the role of a qualified nurse. Many identified areas that they felt needed further input in terms of education and practice. Students identified a number of specific areas in which they felt inadequately prepared for practice. They were concerned that their clinical skills were not adequate for practice, such as the administration of medication, the care of someone having gastrofeeds and the giving of injections. Students also felt unprepared for meeting the health needs of people with learning disabilities. A number felt they need more input in practical communication skills. Students were also concerned about their ability to manage services and provide leadership.

7.6.3 Employers' views of 'fitness to practise'

We interviewed employers who took students from seven of the programmes included in the more detailed part of our study. We explored their involvement in the programmes, their assessment of the strengths and weakness of the programmes and of whether the students were fit for practice at the end of their programme or needed additional training.

Only two employers felt they had close involvement in the design and development of the curriculum. The remaining employers did not have close involvement, nor in most cases did they expect to. Some had established link-posts, but this was often not effective. Most employers did not have the opportunity to influence the design and delivery of the curriculum so that it reflected their specific service needs.

Even though employers did not feel involved in the development of programmes, they did feel that they had a good knowledge of individual programmes and felt able to assess the strengths and weaknesses of the curriculum. They also commented positively on the opportunities that programmes provided for students to be aware of current developments and to develop appropriate values. Most felt that the programmes provided students with opportunities to develop a good understanding of learning disability.

While one employer was impressed with the skills of her employees, all the others expressed serious concerns about students' skill levels. They felt that students were not adequately prepared to practise. One private sector employer who recruited nurses to work in a nursing home specialising in caring for people with learning disabilities and mental health needs commented positively on the utility of a specialist post-registration programme in learning disability but was highly critical of pre-registration education.

7.6.3.1 Preparation for practice

All employers recognised the limitations of students' preparation for practice by providing their own in-house preparation. This took the form of specific induction training plus mentorship or supervision. Some emphasised care skills but one key area included was management especially in areas such as health and safety and risk management. In some cases the employers appeared to provide what amount to a crash programme in key care skills. One private sector employer who recruited nurses to work in a nursing home provided six-months of 'intensive support and training'.

While employers recognised that programmes provided students with opportunities to develop appropriate knowledge and values, they were concerned about the theory-practice gap. They did not view students who successfully complete programmes as ready for practice. Indeed all employers provided top-up training.

7.6.4 Comment

The primary consumers of nurse education considered there were serious limitations to current nurse education. While current nurses felt that their own education left them with deficits in terms of skills and management ability, they felt that changes in the curriculum had improved nurses' knowledge but reduced their skills, and therefore current students were not as well-prepared for practice as their predecessors.

Some students felt that some aspects of education had improved. For example, students on degree programmes and joint social work nursing programmes felt able to exploit opportunities not available to their predecessors. However, in many ways students agreed with their predecessors. While they felt they had an opportunity to develop a sound understanding of and appropriate skills to care for people with learning disabilities, they felt their learning opportunities were limited by the CFP, practical problems in the branch programme and the limitations of practice placements. As a result they did not feel fully prepared for practice, and identified deficits in clinical skills, limitations in their ability to respond to health needs and communicate with people with learning disabilities and lack of preparation for managing services and providing leadership.

Employers, the indirect users of nurse education, also identified limitations in current education. Employers clearly were not confident that pre-registration programmes provided them with fully competent practitioners. They did not feel involved in the design and delivery of programmes and felt they had to fund top-up education in the form of induction training, mentorship or even additional post-registration programmes.

7.7 Final comment and developmental implications

In this section we draw together the main findings of our study and highlight the items that need to be addressed within the nursing curriculum.

The distinctive needs of people with learning disability have, in comparison to the needs of other groups such as people with mental illness, been recognised relatively recently. During this time there have been major shifts in scientific opinion, public attitudes and Government policy, with fluctuations between optimistic views about the ability of services to help individuals reach their full potential and pessimism about the threats posed by and to people with learning disabilities.

- The most effective basis for supporting individuals and their families is through a realistic approach, which should be based on an awareness of the range of needs that people with learning disabilities and their carers have and of the potential that well designed and researched community-based services have for meeting these needs.

While learning disability nurses clearly felt marginalised as the new pattern of services began to develop in the 1970s, we found evidence of confidence that they had a role to play and a contribution to make to these services. It was clear from interviews with users and families that most recognised and valued the contribution and especially the specific expertise of learning disability nurses, seeing them as approachable sources of advice and support. It was clear from our observation of the activities of learning disability nurses within multidisciplinary teams that they not only made a major and distinctive contribution to the team but that this contribution was recognised by other professional, though not unqualified, team members. The pressure from below may be one reason why learning disability nurses emphasised their expertise in and contribution to direct care.

- Learning disability nurses have important skills that are valued by users, carers and members of multiprofessional teams and there is considerable potential for the expansion and development of their contribution.

Direct care was evident in the activities of nurses, especially newly-qualified nurses working in residential settings. However, as nurses gained experience and seniority, the nature of their role and associated patterns of activities changed. Some nurses took on a more specialised role that often involved advising those providing direct care. In this type of activity nurses need to have skills not only in assessing and in providing advice but also in providing appropriate education input and in managing their own time. An alternative career path was movement into the management of services. It was clear that nurses undertaking this role did not feel entirely comfortable, and often sought contact with users to justify their position and create job satisfaction. This tension may be difficult to resolve.

- The provision of systematic support as well as more explicit assistance with career planning and development may offer individuals opportunities to balance the professional and managerial dimensions of their roles.

Education is clearly orientated towards the development of practice. In programme documentation and in our interviews with lecturers and students, it was clear that the prime aim of programmes was to create or enhance learning disability nurses' ability to provide modern and up-to-date care for people with learning disabilities. This could be seen in the clear value base articulated in most programme documentation, in the ways in which knowledge was seen as a means to an end not an end in itself and on the provision of a range of opportunities to develop practical skills.

- The objective of programmes of education should be to develop and enhance the competence of learning disability nurses and to ensure that they are 'fit for practice'.

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The reality of educational provision did not quite match up to the promise. This was particularly evident in the contribution of users and carers. While programme documentation indicated that users and carers were a central focus of the educational process, in reality they were not equal participants. At best their involvement was tokenistic and at worst they were virtually invisible, a source of knowledge and skills but not partners in learning.

- The role of users and carers needs to be reviewed and they need to be treated as active partners not as passive bystanders.

While programmes are designed to ensure or enhance fitness for practice, it was not clear that they were achieving their objectives. If they were, then employers would not feel obliged to provide additional training, which in some instances seemed to amount to a crash programme. While it is important that programmes meet the needs of a range of employers and are not restricted to the needs of a specific one, it was not clear to us that employers were actively involved in the process of programme development and delivery.

- While educational institutions need to ensure that their programmes are fit for academic award, there is clearly scope for more active involvement of employers in the development and delivery of programmes.

It is also important to specify what sort of practice programmes are preparing future nurses for. It appears that most programmes viewed nursing in terms of the direct care of users and support for families and it should therefore be a cause for concern that both current students and current nurses identified limitations of direct care skills.

- The nature and organisation of practice placements should be reviewed so that students are involved in their selection, are properly prepared and there is effective communication between all stakeholders about the aims and objectives of the placement.

It was not clear that programmes were preparing students for broader aspects of their role beyond direct care. While it is appropriate that post-registration education should prepare 'first level' nurses for more specialised roles, it is important that these should consider all aspects of advanced practice not just specialist assessment and interventions but also include areas such as time management and the provision of education. The location of education for management is more problematic. It is clear that some nurses acquire a management component to their role early in their careers and it was not evident that they were systematically prepared for this in pre-registration programmes that had variable inputs in this area.

- The management component in pre-registration education should be made more explicit and systematic and consideration should be given to the professional recognition of post-registration education in this area.

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RESEARCHING PROFESSIONAL EDUCATION

A series from the English National Board for Nursing, Midwifery and Health Visiting

Diversity and Change: the changing roles and education of learning disability nurses

Andy Alaszewski
Bob Gates
Elaine Motherby
Jill Manthorpe
Sam Ayer

This report, in the Board's series *Researching Professional Education*, has been published to make Board-commissioned research readily available to policy makers, practitioners, researchers and educationalists.

This latest report, *Diversity and Change: the changing roles and education of learning disability nurses*, examines the current roles of learning disability nurses within multiprofessional and multi-agency teams in a range of care settings. The research team also examined the effectiveness of current educational provision for learning disability nursing and the contribution of users and carers.

Major differences were identified in the roles of learning disability nurses from the provision of care and support within hospital settings to a diversity of roles and activities providing support for users in a variety of settings. The research shows that learning disability nurses make a major and distinctive contribution to the multiprofessional and multi-agency teams with whom they work. In terms of educational provision, the role of users and carers needs to be reviewed and they need to be treated as active partners not as passive bystanders.

This important report has implications for educational providers, for employers of learning disability nurses and the members of the teams within which learning disability nurses work.

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